

### **CHAPTER 3:**

# COMMUNICATION ASSESSMENT OF YOUNG CHILDREN WITH CLEFT LIP AND / OR PALATE

The aim of this chapter is to critically review the recommended assessment practices for young children with CL/P. This will provide a framework for the development of a generic, and holistic communication assessment protocol and creation of a database for speech-language therapists and audiologists, with an aim to improve the standards of cleft care in a developing country.

#### 3.1 INTRODUCTION

Children born with cleft lip and/or palate (CL/P) are at risk of communication delays and/or disorders and early communication intervention (ECI) can improve outcomes (Bzoch, 2004: 19; Hardin-Jones, Chapman & Scherer 2006: 8; Rossetti, 2001: 264). Early identification of communication delays/disorders requires effective and efficient systems for screening, assessment and referral (Bzoch, 2004: 35; Guralnick, 2005: 74; WHO, 2002: 143).

Parameters and guidelines for the assessment of patients with CL/P, based on consensus of experts from various disciplines in cleft care are available (ACPA, 2007; CSAG, 1998, Eurocran Speech Project, 2000; WHO, 2002). According to these guidelines, the assessment of young children with CL/P needs to be an interdisciplinary and a collaborative process where the



findings contributed by all team members are used in the planning of comprehensive services. Important recommendations regarding the areas of assessment, ages of assessment and procedures for collecting speech samples, recording and analyzing cleft speech across different languages are now available (ACPA, 2007:10-24; Henningsson et al., 2008; 1-17; Sell, 2005: 103-121). The guidelines could be used internationally to ensure consistency and uniformity in reporting speech outcomes.

However, health care services differ from country to country. In the absence of a team-based approach for assessments, speech-language therapists and audiologists in developing countries have a challenging task to assess communication skills in young children with CL/P without follow-up from other team members such as geneticists, occupational therapists, psychologists and social workers. One solution suggested to address this challenge is to 'import' assessment instruments from developed countries. However, this may not be appropriate because of the prevailing cultural and linguistic differences and diversity among countries (Guralnick, 2005: 14; Shonkoff & Meisels, 2000: 433).

Given that personal, environmental and contextual factors greatly impact assessment it is important to develop assessment instruments which are designed for and appropriate to a given context. It is therefore imperative that speech-language therapists and audiologists in a developing country conduct contextually relevant research to adapt an existing assessment tool or develop a new assessment protocol and evaluate its applicability and acceptability. In this chapter, the areas and procedures for assessment of young children with CL/P are described to



identify the features which could be incorporated in the development of a communication assessment protocol.

### 3.2 PURPOSES OF COMMUNICATION ASSESSMENT

Shprintzen and Bardach (1995: 137) explicitly state that the quality of cleft care services depend on accurate diagnosis for planning effective and efficient interventions. The purposes of communication assessment are illustrated in the Figure 3.1.

PURPOSES OF COMMUNICATION ASSESSMENT				
A clinical perspective	<ul> <li>Identifying children with communication delays/disorders early in life</li> <li>Monitoring developmental changes of the child and addressing new concerns of parents (ECI) as the child develops and undergoes cleft repair/s</li> <li>Describing communication difficulties that guide intervention plans</li> <li>Allowing differential diagnosis of contributing etiological factors in order to make appropriate communication intervention decisions</li> <li>Referring to other team members/professionals for implementation of appropriate interventions, for example surgical/medical/dental</li> <li>Storing results in a database to derive data for descriptive statistics (with a view to improving clinical assessments through research)</li> </ul>			
A long term perspective	<ul> <li>Conducting outcome studies to evaluate the impact of individualised treatment or interventions (pre and post treatment/therapeutic interventions)</li> <li>Utilising a database to conduct programme evaluation and clinical audits and to track the progress of cleft care in a particular context.</li> </ul>			

FIGURE 3.1 Purposes of communication assessment of young children with CL/P



(Based on: ACPA, 2007: 24; Bzoch, 2004: 346; D'Antonio, 2002: 27; Hegde, 2008: 119; John et al., 2006: 278; Rossetti, 2001: 88).

Traditionally, the purpose of assessment of young children with CL/P by the speech-language therapists has been to describe speech characteristics commonly associated with CL/P and/or velopharyngeal dysfunction and to plan therapy that is realistic and structured (Kuehn & Moller, 2000: 361). Speech-language therapists and audiologists need to establish and document a presurgical baseline and longitudinal assessments of speech behaviours, for planning surgical and/or dental interventions and modifying inappropriate learned speech behaviours (ACPA, 2007: 23). Speech-language therapists and audiologists who serve on an interdisciplinary cleft team conduct in-depth diagnostic assessments to determine the contributing etiological factors, the need and rationale for physical management procedures, including secondary palatoplasty by consulting with families and team members (Bzoch, 2004: 377; Kummer, 2008: 341; Peterson-Falzone et al., 2010: 272).

In addition to assessment for diagnostic purposes, speech-language assessments serve to monitor changes following interventions (D'Antonio, 2002: 27). Data derived from detailed and structured assessment protocols is required for research and descriptive statistics to provide evidence of the need for ECI and for surgical repair of the cleft. The speech-language assessment results are important to provide a basis for programme evaluation, treatment outcome studies and clinical audits (ACPA, 2007: 24; CSAG, 1998: 104; McLean, Wolery & Bailey, 2004: 14; WHO, 2002: 29). Audit of treatment outcome measures contribute to improve patient care through systematic review of care against specific criteria before determining best treatment protocols and implementation of changes when indicated (John et al., 2006: 273). Scientifically



derived findings that serve to inform clinical practice contribute to cost effectiveness of the interventions that are implemented (John et al., 2006: 273; Zinkin & McConachie, 1995: 58). The evaluation of programme effectiveness is an important issue especially in contexts where resources are limited and there is a need to justify any additional costs such as costs incurred for equipment, materials and professional expertise (WHO, 2002: 29).

Valid, reliable and comprehensive assessment instruments and a database are required to simultaneously fulfil many purposes as presented in Figure 3.1.

# 3.3 RATIONALE FOR A NEW COMMUNICATION ASSESSMENT PROTOCOL IN A DEVELOPING COUNTRY

International recommendations for areas and procedures for assessment (ACPA, 2007; Eurocran 2000) from developed countries are based on the availability of interdisciplinary team and ECI services. The young child with CL/P who undergoes surgical, medical interventions during the early developmental years requires ongoing assessments of communication skills. In this section, the justification for the development of a holistic and generic communication assessment protocol for young children with CL/P, that could be applicable in a developing country, is presented.

Speech-language therapists and audiologists require access to an effective communication assessment protocol that is relevant within the health care context as well as in the family of the child with CL/P. The family resources to cope with the challenges of having a child with CL/P,



their socio-economic status and the literacy levels of the parents with their varying needs for support and information need to be described during assessment. These aspects impact on the child's development and reflect the family's ability to adhere to the treatment protocol. Moreover, it is a basic principle that a child's communication assessment should be conducted in his/her home language(s) and dialects spoken within the home (ACPA, 2007: 8; Hegde, 2008: 12) to ensure valid and reliable assessment results. A holistic approach to assessment that integrates knowledge gained from the fields of ECI and CL/P provides the most comprehensive information on general development, thus guiding intervention to the maximum benefit of the child and his/her family. A generic communication assessment protocol could accommodate individual children and families, while ensuring that all assessment areas are targeted to provide a consistent data collection instrument.

A generic communication assessment protocol would be applicable to the whole population of children with CL/P (with syndromic or non-syndromic clefts) and, simultaneously be useful to identify the unique problem areas associated with each cleft type. Children with CL/P are a heterogeneous group as they may include different types and severity of clefting either with or in the absence of syndromes/sequences. The type of cleft and its severity has a tenuous link with the characteristic communication symptoms of this population (Persson, Elander, Lohmander-Agerskov & Soderpalm, 2002: 407; Shprintzen & Bardach, 1995: 94). The type of cleft should alert the speech-language therapist to consider such relationships for example the variability in resonance and articulation in young children with CL/P is partly attributed to the type of cleft (Peterson-Falzone et al., 2010: 222; Winder, Imagire & Peterson-Falzone, 2004: 101). Children with cleft palate, as opposed to children with cleft lip only, are likely to have velopharyngeal



dysfunction that causes speech and resonance abnormalities (Kummer, 2008: 49). Furthermore, children with cleft palate are at greater risk of otitis media and associated conductive hearing loss due to Eustachian tube dysfunction compared to children with cleft lip only (Peterson-Falzone et al., 2010: 211). A comprehensive communication assessment protocol applicable to all types of cleft with any severity and that captures different characteristics of this heterogeneous population should therefore be very useful.

In addition to the cleft type, it is paramount that the generic assessment instrument be applicable to children with syndromic CL/P in a presence of a sequence or with multiple anomalies as this knowledge guides the speech assessment. For example, children with Velocardiofacial syndrome (VCFS), are at risk of higher occurrence of abnormal speech characteristics (smaller consonant inventories, greater developmental articulation errors and higher frequency of glottal stop use) compared to children with non-syndromic CL/P cases (D'Antonio et al., 2001: 460). Based on the assessment results the speech-language therapists may plan intensive therapy for certain children.

When conducting a communication assessment of young children with CL/P speech-language therapists, should take into account the timing and surgical technique of the cleft repair. Different teams in various centres follow variable treatment protocols such as the surgical technique and additional presurgical orthopaedic/orthodontic treatment that may impact on communication development and skills (Watson et al., 2001: 386). Together with information on the timing of surgery assessments at three age-based stages namely: birth to palate repair (at approximately 12 months of age), immediately after the cleft repair and at a later stage (30 -36 months) provide



valuable information for intervention planning (Scherer & Kaiser, 2007: 362). For example, stop consonants can only be targeted post cleft palate repair. Surgical repair of the cleft at an early age of the child has been proven to result in better speech outcomes (Bzoch, 2004: 322; Chapman et al., 2008: 106; CSAG, 1998: 30; Peterson-Falzone et al., 2010: 150). Cleft repair may, however, be delayed due to various factors such as the health system structure, availability of experienced plastic surgeons and availability of an interdisciplinary team. Despite variations in health care services and the heterogeneous nature of the cleft population a generic communication assessment protocol is necessary to provide consistent data collection instrument and procedures. The results of a generic communication assessment can be compared over time, and data can be entered in a database for future research and outcome studies.

Recognising that young children with CL/P have special health care needs that vary according to their developmental stages, professionals from various disciplines recommend *longitudinal clinical assessments* of children with CL/P (ACPA, 2007: 3; Peterson-Falzone et al., 2010: 232) to monitor development and guide management. For example, in the neonatal stage early identification and treatment of feeding and early identification of hearing problems prior to cleft repair is important. In infancy, mother-child interactions, communication means and functions as precursors to linguistic development, need to be assessed. During the preschool stage (after the cleft repair), there is a shift in concerns regarding feeding, the development of intelligible speech and adequate velopharyngeal functioning (ACPA, 2007: 16; Kuehn & Moller, 2000: 348; Peterson-Falzone et al., 2010: 268). Developmental stages determine the focus of communication assessment necessitating a generic communication assessment protocol that allows for ongoing, serial assessments.



The recommended areas of assessment according to the stages of the child's development are discussed in section 3.4 followed by a discussion of the instruments and procedures for conducting such assessment in section 3.5.

# 3.4 AREAS OF COMMUNICATION ASSESSMENT AND DEVELOPMENTAL ASSESSMENT STAGES

In clinical practice it is crucial to examine all areas of communicative functioning, as well as associated areas related to the child's ability to use language, as shown in Table 3.1.

TABLE 3.1 Areas of communication assessment and developmental assessment stages

AREAS	STAGES				
	Neonatal (0-1 mo.)	Infancy (1-12 mo.)	Toddlerhood (12-36 mo.)	Preschool stage (36-72 mo.)	
Case History	+	+	+	+	
Genetic screening	+	+	+	+	
Feeding	+	+	+	-	
Hearing and	+	+	+	+	
listening skills	-	+	+	+	
Communication interactions, pragmatics, and	+	+	+	+	
speech-language development	-	+	+	+	
Emergent literacy	-	+	+	+	
Orofacial examination and oral motor function for feeding and speech	+	+	+	+	
Speech production	-	+	+	+	
General development	+	+	+	+	



In Table 3.1, + indicate areas requiring communication assessment; (Based on: ACPA, 2007: 13-23; Bzoch, 2004:281-284; Kummer, 2008: 319-372; Peterson Falzone et al., 2010: 265-288; Shprintzen & Bardach, 1995: 176-220; WHO, 2002: 142).

The broad areas of assessment are similar for neonates, infants, toddlers and preschool children with CL/P but the level, content and manner of assessment needs to be adapted to the developmental stages of the child. The reasons for conducting assessment in specific aspects within each area of assessment is presented according to the developmental stage of the child are discussed below.

#### 3.4.1 Case history

A standard and common procedure used by speech-language therapists and audiologists is to start the assessment with a case history of the child. To plan and implement effective early communication intervention, the case history should include demographic information, family context, cultural background, bilingual/multilingual status, education, occupation, and general level of sophistication of the family (Guralnick, 2005: 137; Hegde, 2008: 12; Paul, 2007: 24).

At every stage of the child's development the assessment should include a comprehensive clinical history. The major elements of the case history in the neonatal stage are pre- and postnatal development history, family history, medical history and physical examination (Kummer, 2008: 322-323). In sourcing the prenatal history, information needs to be elicited about prenatal history, such as maternal illnesses, chronic conditions, use of medications, use of alcohol, use of tobacco, or substance abuse during pregnancy (Wyszynski, 2002: 305).



Furthermore, a detailed birth history including birth weight and the general condition of the neonate should also be obtained. The perceptions of the parents and their concerns at each stage of development should also be determined (Hegde, 2008: 119). For example, in the neonatal stage the main concern of parents is usually feeding, but as the child grows, develops and the cleft is surgically repaired, new concerns such as speech-language development arise that need to be addressed.

During the child's developmental progress speech-language therapists and audiologists should continually obtain further information about the child's medical-surgical treatment, essentially noting age at time of cleft surgery and any other surgeries such as the insertion of grommets for middle ear problems (Hegde, 2008: 119) as this information is important in planning ECI and management of the communication delay/disorder. Peterson-Falzone et al. (2010: 265) stated that 'children with CL/P receive continuing interdisciplinary care throughout childhood and the history obtained during the initial interview will provide only a glimpse of an ever-changing story that will unfold over time'.

Part of the holistic evaluation of every child with a cleft lip and palate is a genetic screening, as clefts are associated with an estimated 350 syndromes and a high probability exists that additional anomalies may be present in the child (ACPA, 2007: 11; Gerber, 2001: 132).

#### 3.4.2 Genetic screening

Obtaining information pertaining to any family history of clefting is recommended for selective referral of cases for geneticist's assessment (Gerber, 2001: 142) as 53% patients with cleft are



reported to have a syndrome and new syndromes are discovered continually (Gerber, 2001: 132). Genetic screening is necessary to plan management of potential medical, developmental, communication delays/disorders and provide counselling and family support (Kummer, 2008: 90-91). All clinicians including speech-language therapists should be aware of the importance and possibility of multiple anomaly syndromes. They should carefully obtain a description of family characteristics, phenotypical descriptions and be prepared to make referrals and consult with team (Shprintzen, 1997: 49).

Genetic screening is a collaborative process whereby other team members such as surgeons, paediatricians and speech-language therapists can help identify children who may need referrals to a geneticist and for genetic study. For example, speech-language therapists may identify communication behaviours and phenotypical features in children with VCFS during the communication assessment and refer the child for genetic evaluation and confirmation of the syndrome.

#### 3.4.3 Feeding

Speech-language therapists have an important role in the interdisciplinary team (in conjunction with nurses and paediatricians) to assess the swallowing and feeding ability of the child with CL/P, in order to make recommendations regarding feeding interventions and parental support. According to Arvedson and Brodsky (2002: 528), at the *neonatal stage* three important aspects of feeding assessment are: adequate oral sensorimotor development, availability of nutritionally adequate food and the interaction between the caregiver and the infant. Neonatal feeding



assessment should also include the state of the neonate during the feed, the feeding time, type of milk (breast/formula milk), equipment used for feeding, and positioning of the neonate (Shprintzen & Bardach, 1995: 165; Watson et al., 2001: 141). Clinical signs and symptoms of an airway deficit and upper airway obstruction such as inspiratory stridor, glossoptosis and micrognathis (as in cases with Pierre Robin Sequence) should signal the need for in-depth feeding assessment (with instruments if necessary) by an interdisciplinary team (Arvedson & Brodsky, 2002: 530; Watson et al., 2001: 143). The *infant stage* is a transition/weaning phase from breast/bottle feed to semi-solid diet therefore, assessment of sip-swallow and appropriate tongue movements, pre-chewing skills and ability to direct the feed towards the oropharynx need to be assessed. Infants with neurological problems, airway disorders, Pierre Robin sequence and pre-term infants are at risk of persistent, feeding problems due to abnormal oral motor function (Reid, Kilpatrick & Reilly, 2006: 708). At the toddler stage feeding assessment should include assessment of oral motor functions such as lip closure, chewing, ability of the tongue to direct bolus towards the oropharynx and swallowing. Feeding assessments also identify parental needs and concerns that need to be addressed during intervention. In addition, weight gain should be monitored.

Reid et al. (2006: 708) found a high prevalence of poor feeders in their clinical cohort, and they concluded that early detection and management of feeding difficulties is important. However, their study also indicated that by three months of age poor feeding is likely to resolve as cleft repair improves the ability to feed. But feeding problems may persist in young children with CL/P and neurological involvement, Pierre Robin sequence or in children HIV/AIDS. Therefore, an assessment protocol should include feeding assessment procedures from neonatal stage through to toddler stage until there are no concerns for the child's feeding.



### 3.4.4 Hearing and listening skills

Conducting hearing evaluations to diagnose hearing loss and to monitor hearing in developmental stages of young children with CL/P is crucial (ACPA, 2007: 13, Broen et al., 1996: 132; Bzoch, 2004:361; Kernahan, Rosenstein & Dado, 1990: 236; Peterson-Falzone et al., 2010: 216; Watson et al., 2001: 222) as the incidence of middle ear disease is very high. Furthermore, children with syndromes/sequences are at risk of sensorineural or mixed hearing loss (Peterson-Falzone et al., 2010: 215; Shprintzen & Bardach, 1995: 164). A persistent/fluctuating hearing loss adversely affects communication development and may have consequences for cognitive development of the child (JCIH, 2007: 898). Making a differential diagnosis of hearing loss requires the collaboration of the audiologist, physician and parents of the child with CL/P.

Examination of the ears for phenotypic features (for example: atresia), newborn hearing screening, and if indicated, diagnostic hearing evaluations need to be conducted at the *neonatal stage* (ACPA, 2007: 10). Additional high risk factors for hearing loss should be identified from the perinatal history. At the *infant stage* an assessment of hearing sensitivity for each ear and hearing screening should be continued at least annually through to the age of six years to ensure adequate monitoring of hearing by an audiologist and ENT specialist (ACPA, 2007: 11). At the *toddler stage* audiologists should continue to monitor hearing ability and middle ear functioning as in the early years, middle ear disease may be recurrent (Jocelyn, Maureen, Penko & Rode, 1996: 533; Blakely & Brockman, 1995: 30; Kritzinger et al., 1996: 80; Peterson-Falzone et al., 2010: 216). Schonweiler et al. (1999: 214), conducted a large-scale study of 370 toddlers with



CL/P, and found that even mild fluctuating hearing loss had a major influence upon speech and language, necessitating regular monitoring of hearing. Even in the absence of otologic disease or hearing loss, *preschool age* children with CL/P require annual hearing evaluations to adequately monitor hearing (ACPA, 2007: 14). Children presenting late for surgical repair also require a hearing assessment to determine hearing acuity and identify hearing loss. Even children identified with congenital hearing loss, require monitoring of their hearing levels (JCIH, 2007: 901).

In addition to monitoring hearing levels, the impact of hearing impairment on the neuromotor encoding and auditory decoding skills of the infant with CL/P and on listening behaviour, should be assessed. The latter has not received sufficient attention from researchers. Auditory processing has a negative impact on communication development of young children (Cole & Flexer, 2007: 76; Hugo et al. 2000: 141; Kritzinger & Louw, 2002: 8). Therefore, young children with CL/P require regular hearing evaluations and listening skills evaluations.

#### 3.4.5 Communication interactions, pragmatics and speech-language development

Screening and assessment of communication interactions, pragmatics and speech-language development conducted from the neonatal stage (refer to Table 3.1) allows speech-language therapists and audiologists to identify problems early and to take preventive measures to minimise the negative impact of the cleft (ACPA, 2007: 23; Bzoch, 2004: 408; Scherer et al., 2008: 25). If language delays or disorders are identified, during a team visit screening of



communication functions, then a scheduled and structured in depth language assessment should be conducted (Bzoch, 2004: 378; Peterson-Falzone et al., 2010: 267).

Assessment of parent-child interactions is important to the child's development and long term care (ACPA, 2004: 11; Nackashi, Dedlow & Dixon-Wood, 2004: 281). At the neonatal stage communication assessments should include the many psychosocial concerns of parents to address the information needs of parents and to help them adjust to the neonate with a CL/P (Peterson-Falzone et al., 2010: 267). ECI studies of children with CL/P have reported problems with communication interactions, functions and parent-infant bonding due to the cleft condition and related stress factors, such as feeding problems (Hardin-Jones, Chapman & Scherer, 2006: 8; Neiman & Savage, 1997: 223; Scherer & Kaiser, 2007: 355). The assessment of infants with CL/P needs to focus on: communication behaviour (parent-child interactions), communication means (nonverbal, gestures, verbal) and receptive and expressive language skills (especially phonological development and vocabulary acquisition). The direct effect of the cleft palate on the babbling, vocalisations and prelinguistic communication behaviours, in infancy, can be monitored through assessments prior to the surgical repair of cleft palate and compared later with the post cleft palate repair assessments in the toddler stage of development (Chapman et al., 2003: 193).

Assessment of the prelinguistic communication skills, receptive and expressive language skills of *toddlers* with CL/P is recommended to be carried out at least twice annually until the age of two years (ACPA, 2007: 23). Specific aspects of speech-language development screening in toddlers should include comprehension, communicative gestures, pragmatics, phoneme repertoire, syllable structure, word use and play, since these communicative behaviours indicate whether the



child is following a trajectory of normal development (Rossetti, 2001: 137; Shprintzen & Bardach, 1995: 183). The findings of Hardin-Jones and Chapman, (2008: 95) indicate that speech-language therapists can appropriately identify toddlers with cleft palate who are at risk for later delays in speech-language development. They reported the presence or absence of oral stop consonants as a key clinical finding that may assist speech-language therapists in identifying children who will need early intervention services (Hardin-Jones & Chapman, 2008: 95).

A longitudinal monitoring of progress in phonological development permits the identification of new concerns on a timely basis (ACPA, 2007: 13; Nackashi, Dedlow & Dixon-Wood, 2004: 280). At the *preschool stage* an assessment of both early receptive and expressive language skills is recommended for preschoolers with CL/P as research has proven that a wide range of language delays/disorders occur more frequently among children with cleft than children without cleft (Bzoch, 2004: 6; Hardin-Jones & Jones, 2005: 11; Morris & Ozanne, 2003: 468). Screening results during team visits are used to identify children with CL/P and language delays/disorders and based on these results, in-depth language assessments by the speech-language therapist are scheduled. In the preschool stage, the language screening should include the child's receptive and expressive vocabulary, phonology, appropriate expressive use of morphology and syntax, and pragmatics (Shprintzen & Bardach, 1995: 169).

#### 3.4.6 Emergent literacy skills

Literacy skills are language based and the development of emergent literacy extends from infancy through preschool years (Pence & Justice, 2008: 224). Research on young children with



CL/P showed that 30% to 40% young children with CL/P had reading difficulties (Broen et al., 1998; Richman & Ryan, 2003: 156). Hence communication assessment protocols for young children with CL/P should include emergent literacy skills as an assessment area so that parents can be given appropriate guidance and future literacy development can be facilitated. Early intervention to prevent later reading and writing difficulties in children with CL/P is important to attaining the goal of school readiness at five years of age (Blakely & Brockman, 1995: 25; Zimmerman & Castilleja, 2005: 239). Assessment for emergent literacy skills should start at the infant stage (refer Table 3.1). *Infants*' early language and literacy experiences, such as exposure to books, attending to nursery rhymes, looking at pictures and joint story book reading interactions with their parents are observable early literacy development behaviours which need to be assessed (Hoff, 2005: 398). At the *toddler stage* assessing adult-child shared book reading that stimulates verbal interaction to enhance language development and print knowledge, and assessing activities that highlight the relations between print and speech need to be included in the assessment (Restrepo & Towle-Harmon, 2008: 10). Emergent literacy development is a continuous process. Children with CL/P who display phonetic and phonologic developmental disorders may experience difficulty in developing reading and writing skills (Nathan, Stackhouse, Goulandris & Snowling, 2004: 377) Information obtained from assessment results can inform ECI and recommendations to parents of children with CL/P on emerging literacy. Emergent literacy skills' assessment at the *preschool stage* should include the child's knowledge of environmental print, knowledge of print conventions, and letter-name and letter-sound knowledge, as well as analyses of narrative abilities (Kaderavek & Justice, 2000: 82-93; Pence & Justice, 2008: 225; Restrepo & Towle-Harmon, 2008: 10). Assessment of specific literacy aspects that the child is developing, indicate the emergent literacy level.



#### 3.4.7 Orofacial structures and oral motor function

Examination of orofacial structures and oral motor functions should always be included as part of the communication assessment in young children with CL/P (Kummer, 2008: 351). Oral motor function needs to be assessed to differentiate the role of the structural restrictions (obligatory speech errors) from impairments of speech function (compensatory errors) (Peterson-Falzone et al., 2006: 183; Shprintzen & Bardach, 1995: 184). Furthermore, if abnormal facial features or dysmorphology are observed a genetic evaluation may be suggested to identify the presence of a syndrome or sequence.

At the *neonatal stage* a brief screening examination of the neonate's face, eyes, ears and mouth is generally conducted by the midwife, paediatrician or doctor just after birth. A speech-language therapist may need to be involved to assess the neonate's baseline description of the type and severity of cleft, structures that relate to speech production and the impact on feeding (ACPA, 2007: 11). Assessment includes checking suckling reflex and a detailed examination that may help distinguish neonates with associated malformations or a syndrome as the results of the assessment determine the management of the neonate. At the *infant stage* speech-language therapists and audiologists should describe the phenotypic facial features (for example profile, eyes, and ears) of an infant with CL/P that may indicate the presence of a sequence or syndrome as part of genetic screening of the infant. They may contribute to a diagnosis by discussing their observations with other team members for example the paediatrician and/or geneticist (Gerber, 2001: 130; Kummer, 2008: 88-91; Shprintzen, 1997: 152). The type of cleft should also be noted and whether it has been repaired or not should be recorded. Although complete



assessment of the oral motor function is only possible when the infant is older and able to cooperate, observations of feeding allow assessment of oral motor function as well as spontaneous movements such as pursing lips when the infant kisses a parent (Shprintzen & Bardach, 1995: 184). The speech-language therapist should conduct an orofacial examination and oral motor function assessment again at the toddler stage and post cleft repair to determine if there are physical factors that could be interfering with articulation and resonance. For example, the labial competence, dental occlusion, the hard palate, the oral structure of the velum, the uvula, tonsils and the tongue mobility and accuracy of tongue movements (Bzoch, 2004: 471; Kummer, 2008: 350; Peterson-Falzone et al., 2006: 104). The presence of palatal fistulae should be determined and the effects on eating, drinking and speech should be assessed. Dental structures should be examined for any occlusal problems, supernumery or missing teeth (Shprintzen, 1997: 158). The soft palate should also be examined carefully as hypernasality may be due to inadequate velopharyngeal closure or a submucous cleft palate may be present causing hypernasality. Visual inspection of velar closure may however, be deceptive (Shprintzen & Bardach, 1995: 189) and instrumental assessments that provide more diagnostic information are recommended for further examination of the velopharyngeal closure. *Preschool age* children with CL/P are at an increased risk of developing and habituating structurally based speech disorders. At this stage, facial growth is taking place and relationships between structures may change. The examination of the orofacial structures at every stage of development helps to identify the contributing etiological factors to abnormal speech (Kuehn & Henne, 2003: 105) such as maxillary-mandibular disproportion, dental malocclusions. The structural anomalies may appear to be significant but may not have an impact on speech articulation (for example a fistula or a large oropharyngeal space). An orofacial examination is necessary in children with



CL/P in conjunction with a perceptual speech assessment for the accurate interpretation of speech errors that may require physical management and/or speech-language therapy (Kummer, 2008: 361; Peterson-Falzone et al., 2006: 69).

#### 3.4.8 Speech production

As a CL/P may have a pervasive effect on speech production, it is crucial that the speech-language therapist conducts a thorough assessment of speech, voice and resonance (Hardin-Jones & Jones, 2005: 12; Kummer 2008, 328-332; Peterson-Falzone et al., 2010: 268; Sell et al., 1999: 17-33; Trost-Cardamone, 2004: 463-468; Whitehill, 2002: 55). Based on the results of the speech-production assessment, speech-language therapists together with team members make treatment and management decisions (ACPA, 2007: 23; D'Antonio, 2002) therefore a reliable and valid speech production assessment is required.

As illustrated in Table 3.1 the *neonatal stage* speech production assessment is not practicable since language-specific speech production starts at the infant stage.

At the *infant stage* the size of consonant inventories and early developing consonants during the infant's babbling stage should be assessed as early speech sound development is a good predictor of early word productions and later speech production accuracy (Chapman et al., 2003: 193; Peterson-Falzone et al., 2010: 234). Infants who have limited oral-motor practice through vocalisations, especially prior to cleft palate repair, are likely to develop phonological articulation errors (Peterson-Falzone et al., 2010: 235; Watson et al., 2001: 197). Early speech



production assessments provides therapists and parents with information regarding the quantity and quality of consonants' inventories and speech-language therapists can guide parents to stimulate the child with CL/P to produce a variety of consonants (Watson et al., 2001: 192). Toddlers with CL/P remain at risk for both phonetically and phonologically based speech sound disorders (Peterson-Falzone et al., 2010: 234). The assessment of speech production postsurgery in toddlers should include the process and pattern of phonological development as well as phonetic errors (Peterson-Falzone, 2010: 235). Although speech production is reported to improve as normal speech immaturities get resolved and the cleft is repaired, speech production should be assessed and tracked to determine changes in post-operative speech production (Chapman et al., 2003: 177). Assessment of speech sound production at the toddler stage should also identify any compensatory strategies that the toddler may be developing and which risk becoming habitual (Peterson-Falzone et al., 2006: 7; Watson et al., 2001: 192). Information gained from such speech analyses helps the speech-language therapist to efficiently plan therapy and correct the child's speech disorder. At the *preschool stage* speech assessments and orofacial examinations are necessary to identify contributing etiological factors of speech disorders such velopharyngeal inadequacy or insufficiency, palatal fistulae, abnormal dentition and malocclusion, and abnormal learned speech patterns (Peterson-Falzone et al., 2010: 237; Watson et al., 2001: 196). Children with CL/P often develop compensatory articulation patterns/active speech characteristics that should be differentiated from obligatory errors/passive errors (Harding & Grunwell, 1998: 330; Kummer, 2008: 328). Furthermore, these need to be distinguished from developmental speech articulation errors that children may exhibit, such as omissions (Peterson-Falzone et al., 2010: 232). Such differential diagnostic speech production assessments are



required at the preschool stage to determine whether speech-language therapy and/or physical management are required (Peterson-Falzone et al., 2006: 87).

#### 3.4.9 General developmental screening

Assessment of developmental domains, such as cognitive function, motor development and personal social behaviour is particularly relevant for young children with CL/P (Blackman, 1995: 13; Kritzinger & Louw, 2002: 4; Paul, 2007: 38; Rossetti, 2001: 147). Motor milestones are an indicator of general development and relate to speech and language acquisition (Shprintzen & Bardach, 1995: 182). Children with CL/P are a heterogeneous group with known risk factors for developmental delays that may be due to medical diagnoses and environmental factors (Broen et al., 1998: 683; Neiman & Savage, 1997: 218). Screening of general development is required to determine the level of functioning of the child. Identification of delays and unusual patterns in his/her development will necessitate referral of the child to the services of an early interventionist, psychologist, paediatrician and nursing personnel as the goal of early intervention is holistic patient care (Guralnick, 2005: 137; Wyszynski, 2002: 304).

During the *neonatal stage*, risks associated with development such as syndromes should be identified and then followed up during the infant stage by team assessments as developmental delays may appear later during the infant stage. Developmental domains such as motor development, self-help, cognitive and social interaction skills should be included in assessments of *infants* with CL/P. Neiman and Savage (1997: 224) compared developmental quotients of 186 infants and toddlers with CL/P at 5 months, 13 months and 36 months with normative



sample group and found delays in motor and cognitive development at 5 months and attributed it to surgical events and feeding difficulties. As communication development is related to cognitive and motor development it is important to screen the general development of the infant to determine the level of communication assessment. At the toddler stage continued developmental screening is necessary as attainment of developmental milestones and psychosocial adjustment continues to be a matter of concern at toddler stage (Nackashi, Dedlow & Dixon-Wood, 2004: 283). In a study by Neiman and Savage (1997: 223) toddlers with CL/P who were developmentally delayed in motor development, were also significantly delayed in expressive language. Delayed communication development is the most important common symptom of developmental delay in children younger than three years (Bzoch, 2004: 402; Rossetti, 2001: 106). Broen et al. (1998: 685) based on a comparative study of children with cleft and non-cleft children, also reported that the differences identified in cognitive skills were All developmental areas are interrelated, and development in one area language based. influences either positively or negatively development in another area (Papalia, Olds, & Feldman, 2002: 7). For example, active participation in play, exploration of the environment facilitates communication, speech-language development (Rossetti, 2001: 226). based on such a holistic approach to assessment the speech-language therapist can plan an effective communication intervention plan. At the *preschool stage* developmental screening with a special emphasis on cognitive and psychosocial functioning is a pivotal need, as preschoolers with CL/P may face social adjustment issues that children with a facial deformity may experience (Wyszynski, 2002: 303). Information sourced from parents of the child with CL/P regarding social interactions can provide indicators of possible subtle language impairments (Shprintzen & Bardach, 1995: 202).



In conclusion, serial assessments conducted at regular intervals by a team of health care professionals can serve to better inform the interventions. Serial assessments are necessary to identify young children with communication problems and track developmental progress of those children. Many interrelated factors (child's biological factors and his/her environment) play a role in the child's development implying that the assessment approach should be generic, comprehensive and holistic.

In section 3.4, the areas of assessment at the various developmental stages and the related justifications were presented. In the following section, the procedures and instruments that speech-language therapists and audiologists use to assess these areas are critically reviewed.

# 3.5 ASSESSMENT PROCEDURES AND INSTRUMENTS FOR YOUNG CHILDREN WITH CLEFT LIP AND / OR PALATE

Given the importance of communication assessment, it is imperative that the assessment instruments selected are appropriate, valid, reliable, and fulfil the purposes of assessment (Bagnato, Neisworth & Munson, 1997: 35; Blackman 1995: 79; Weitzner-Lin, 2004: 36). Children with CL/P have typical speech production errors that require a specific framework to best describe these errors. Research reports and debates on procedures and measurement standardization of speech of young children with CL/P abound in academic literature (Kuehn & Moller, 2000: 348). However, communication development can be assessed by using general assessment instruments and procedures as it is not necessary to have specific procedures just for children with CL/P.



Professionals should be sensitive and flexible in the selection and use of assessment procedures and accommodate the diversity of children with CL/P and their families (ACPA, 2007: 8). Recommendations for appropriate assessment instruments and procedures to assess the various areas of communication (Table 3.1) in young children with CL/P are discussed in the following sections.

#### 3.5.1 Procedures for case history taking

Obtaining a reliable case history is the first step in any assessment procedure. The speech-language therapist and audiologist may obtain medical and surgical history from hospital records, but these may not be complete or accessible to them. Parent interviews are therefore important to complete the required information/history and to verify the information from hospital records (Blackman, 1995: 63-64) as parents often possess information unavailable to professionals. The procedure of taking case history provides an opportunity to make contact with the parents of the child with CL/P. The ACPA (2007: 11) also recommends arranging for a psychosocial interview of the family to obtain information regarding the family history and adjustment levels to the child, and to assess cultural and linguistic influences affecting the family and to gain a better understanding of family background.

Socio-demographic information may be gathered by using standard case history questionnaire forms (Hegde, 2008: 339). A variety of assessment instruments, to produce the most valid appraisal of developmental status and to achieve the related assessment purposes of



identification, prescription, progress evaluation and prediction should be used (Bagnato et al., 1997: 18; Rossetti, 2001: 147).

#### 3.5.2 Genetic screening

Genetic screening consists of case history information and clinical observations. A case history that probes pregnancy and family history might indicate genetic factors in the child with CL/P can be elicited through parent interview schedules and questionnaires (for e.g. Genetic Screening Questionnaire, accessible from:

http://www.acpa-cpa.org/educMeetings/educ\_ScreeningTools.htm).

Based on a family history of clefting and observations of phenotypical descriptions that may be guided by checklists during genetic screening such as CHRIB case history form (Louw & Kritzinger, 1995) so that the presence of obvious phenotypic features (such as in Treacher Collins syndrome or Apert syndrome), can be identified. Gerber (2001: 142) recommends selective referral of cases for genetic assessment. Genetic screening is an ongoing process because some structural anomalies are not obvious at birth and cannot be detected until later childhood. Speech-language therapists should include genetic screening procedures as a geneticist may not be available in all multidisciplinary teams.

#### 3.5.3 Feeding assessment

Feeding assessments at every stage of development should begin with a structured interview designed to capture medical (risk factors for feeding and/or developmental problems), surgical



and family resources and needs (Masarei et al., 2007: 321; Reid et al., 2006: 703; Young et al., 2001: 57). Mothers/caretakers may be questioned on whether coughing, choking, gagging, nasal regurgitation, or a wet or gurgly voice quality (i.e., feeding sequelae) occurs during or immediately after feeding. Speech-language therapists may conduct direct assessments by observing specific feeding behaviours and/or conducting the feeding assessment according to a checklist at the respective development stage of the child (Table 3.2).

**TABLE 3.2** Feeding assessment procedures

	Stages			
Procedures	Neonatal	Infancy	Toddlerhood	Preschool stage
Medical records and parental/care giver reports	Peri-natal history and parents'/care givers' concerns about feeding	Medical records of child's growth, developmental history, surgical & medical history Parental reports of feeding concerns		
Observations Check-lists (Masarei et al., 2004)	Infant state Observe breathing- sucking- swallowing sequence Feeding method, equipment used and feeding options (breast milk/formula milk)  Positioning of the neonate during feeding	Feeding method, equipment used Weaning/ transition to semisolid food Examinations of airway, neuromotor control, chest examination, examination for submucous cleft	Post cleft palate repair assessment Examine oral-motor function Observe and question parents regarding nutrition, chewing, swallowing, nasal regurgitation	-
Instrumental Procedures	-	In severe cases, Fibreoptic endoscopic evaluation of swallowing (FEES) by surgeon and/or Video fluoroscopic swallowing study (VFSS) by radiologist with speech-language therapist		

(Based on: Arvedson & Brodsky, 2002: 527; Kummer, 2008: 144-145; Masarei et al., 2007: 321; Reid et al., 2006: 704).

The feeding assessment procedure should be specific to the developmental stage of the child with CL/P. At the neonatal stage, the ability to sustain effective sucking and coordinate respiration with the suck/swallow reflex should be assessed (Watson et al., 2001: 137). When feeding



difficulties are significant, such as airway compromise (for example in cases with Pierre Robin sequence) which may be indicated by coughing, choking, colour change, and increased respiratory rate, objective studies of swallowing function need to be performed (Shprintzen & Bardach, 1995: 67).

For many children born with CL/P, assessment checklists of the feeding patterns are appropriate and sufficient as the feeding process may only require minor adjustments (Arvedson & Brodsky, 2002: 189). Recommendations for assistive feeding devices and safe swallowing strategies for infants with CL/P can be made based on this assessment instrument (Masarei et al., 2007: 326).

#### 3.5.4 Hearing and listening evaluations

Hearing impairment in young children with CL/P may be fluctuating, static, progressive or have delayed onset (Shprintzen & Bardach, 1995: 148). Therefore, ACPA (2007: 14) recommends repeating hearing evaluations annually. The approach adopted to assess a child's hearing depends on the developmental stage of the child (Table 3.3). Ear-specific assessment is the goal for both behavioural and physiologic procedures because a unilateral hearing loss, even in the presence of a normal-hearing ear, may place a child at significant developmental and/or educational risk (ASHA, 2004: 6). Technological advances such as evoked otoacoustic emissions (OAE) and auditory brainstem response (ABR) have made it possible to diagnose hearing impairments as early as the neonatal stage (Burkard, Don, & Eggermont, 2007: 260; Northern & Downs, 2002: 266). Hearing evaluation procedures are summarised in the following Table 3.3



**TABLE 3.3** Hearing evaluations

	STAGES				
Procedures	Neonatal	Infancy	Toddlerhood	Preschool stage	
Case history	High risk register	Genetic Screening,			
		Medic	cal (otitis media) and	ear surgery,	
		Otitis media or pressure equalization ear surgery (grommets/T-tubes)			
Examine and	Examine ears for	Exan	nine ears for phenoty	pe features	
Observe	phenotype features	Observe auditory behaviour and listening skills			
Electroacoustic instruments used in appropriate quiet environment and when necessary sound treated rooms	New born hearing screening with: Otoacoustic Emissions (OAE) &/or auditory brain stem evoked responses (ABR)  Immittance measures using high frequency probe	Otoacoustic Emissions (OAE)  Auditory Brain stem evoked responses (ABR)  Immittance measures using high frequency probe	Immittance tests using 220 Hz probe  Free field audiometry (VRA)  Auditory Brain stem evoked responses (ABR)	Diagnostic audiometry (PTA) ear specific with conditioning and masking if necessary and obtain thresholds of hearing  Speech audiometry  Immittance tests using 220 Hz probe	

Sources: (ACPA, 2007: 13-14; ASHA, 2004: <a href="http://www.asha.org/members/deskref/default">http://www.asha.org/members/deskref/default</a>; Cole & Flexer, 2007: 110-111; Hugo et al, 2000: 47; JCIH, 2007: 899).

Hearing evaluation procedures require the use of expensive electroacoustic instruments, infrastructure such as sound proof booths or sound treated rooms for pure tone audiometry as well as audiologists specifically trained in conducting hearing evaluations of neonates, infants, toddlers and pre-school age children (JCIH, 2007: 910).



Although hearing procedures have been specified, information on auditory processing and listening skills is still lacking in young children with CL/P. The Listening Evaluation Scale (Hugo et al., 2000: 47-53) assesses listening in two situations:-

- during the communication assessment where the child's listening behaviour is observed and rated according to a three point rating scale a score of 1 indicates 'good listening' and a score of 3 indicates 'poor' listening
- during hearing evaluation in which standard audiometric techniques are utilised.
   The consistency of responses during hearing evaluations and distractibility are also rated on a three point scale.

The scale provides an indication of poor as well as good listeners. This listening evaluation procedure is easily applicable, rapid and can be useful for intervention programmes by giving equal attention to hearing and listening impairment (Hugo et al., 2000: 52).

# 3.5.5 Assessment of communication interactions, pragmatics and speech-language development

A comprehensive assessment of communication interaction, functions and pragmatics is performed by speech-language therapists; they use a combination of standardised tests, developmental scales, criterion-referenced assessment procedures and behavioural observations (Owens, 2001: 275; Peterson-Falzone et al., 2010: 280). In early communication assessment, the use of criterion-referenced assessment procedures has gained preference over norm-referenced assessment, as the developmental rate of very young children is variable. A criterion-based assessment approach describes the child's functioning along a continuum of developmentally



sequenced objectives and facilitates intervention planning (Bagnato et al., 1997: 8; Kritzinger & Louw, 2002: 5; Rossetti, 2001: 100).

The assessment of speech-language development of children with CL/P can be conducted by selecting procedures and tools developed in the field of ECI to identify those who may then require an in depth comprehensive language assessment. A functional, descriptive and qualitative approach to the assessment of communication interaction and functions is recommended to obtain information about infants and toddlers at risk for communication delays and/or disorders. Research has demonstrated that parent questionnaires can be a valid and time efficient means of screening speech-language development when compared with a speechlanguage screening (Scherer & D'Antonio, 1995: 12). A joint parent-professional assessment process is combined with direct ongoing naturalistic observations of a child, allowing speechlanguage therapists to identify children who will require in-depth communication assessments (Kuehn & Moller, 2000: 355; Peterson-Falzone et al., 2010: 280; Prizant & Wetherby in Blackman, 1995: 156; Shonkoff & Meisels, 2000: 270). A checklist of receptive and expressive language skills that includes an articulation screener and behaviours considered as precursors to language development and emergent literacy skills should be utilised. Examples of procedures and instruments used in early communication intervention that may be used for communication assessment of young children with CL/P are shown in Table 3.4.



TABLE 3.4 Assessment procedures and instruments for communication interactions, pragmatics and speech-language development

	Stages			
Procedures & Instruments	Neonatal	Infancy	Toddlerhood	Preschool stage
Parent questionnaire for screening early communication speech-language development	Smile, eye gaze, responsiveness	Parent child interactions Gestures, social interactions, joint attention and behaviour regulation	Social interactions, joint attention and behaviour regulation	Receptive and expressive vocabulary, use of syntax and conversational skills
Observations of communication interactions functions & pragmatics Elicit language development information	Interaction- attachment	Informal observations to identify children who require a comprehensive language assessment.	Criterion referenced measure of communication and interaction; preverbal and verbal aspects of interaction are observed (0-3 years)	Direct child- centred assessment of language development
Examples of instruments	MacArthur-Bates Communicative Development Inventory (CDI) (Fenson et al., 1993)  The Rossetti Infant-Toddler Language Scale: A Measure of Communication and Interaction (Rossetti, 1990)  Observation of Communication Interaction (Klein & Briggs, 1987)  Communication and symbolic behaviour scales (Wetherby & Prizant, 1995)			Preschool Language Scale (PLS-4) (Zimmerman Steiner & Pond, 2002). Pragmatics Profile of everyday language (Dewart & Summers: 1995)

Sources: (Blackman, 1995; Hegde, 2008: 258-262, Kritzinger & Louw, 2002: 7; Rossetti, 2001: 144)

Early speech-language development assessment requires knowledge of the developmental patterns and stages of both receptive and expressive language skills. During the emerging language development stage children also develop emergent literacy skills which need to be assessed.



### 3.5.6 Emergent literacy skills assessment

Questionnaires and parent interviews may be used to describe parental practices regarding the emergent literacy development.

TABLE 3.5 Assessment procedures for emergent literacy skills

Procedures	STAGES			
	Neonatal	Infancy	Toddlerhood	Preschool stage
Parent report based on a questionnaire/ checklist  Speech-language therapists' observations  Checklists  For example, Kadevarek & Justice (2000: 82-93);	-	Home environment for literacy development Infant's interest in books, handling books, joint book reading practices  Types of books parents read to	Recognising pictures  Print knowledge Joint book reading with parent (facilitation of emergent literacy development)  Phonological	Phonological awareness, identifying initial sounds, rhyming words, print knowledge  Listening to stories and retelling them, writing own name
Van Heerden & Kritzinger (2008: 37-48).		child	development	

Sources: (Hegde, 2008: 278-279; Kritzinger and Louw, 1997: 2; Nathan et al., 2004: 377-391;

Pence & Justice, 2008: 225; Van Heerden & Kritzinger, 2008: 48).

Integrating emergent literacy skills assessments using procedures and instruments described in Table 3.5 is the basis for appropriate recommendations to parents of young children with CL/P and an opportunity to help improve future academic performance of their children.



#### 3.5.7 Orofacial examination

Various forms, checklists and guidelines are available to guide an orofacial examination.

**TABLE 3.6** Procedures for orofacial examinations

<b>Procedures and</b>	STAGES				
equipment	Neonatal	Infancy	Toddlerhood	Preschool stage	
Examination, observations (visual inspections) of oral structures and elicitation tasks of the speech production mechanism: Lips, teeth, tongue, jaw, velopharyngeal, and hard palate and respiratory system Use gloves, flashlight, tongue depressors, dental mirror, alcohol swabs to wipe surfaces and equipment	Presurgical observations of oral structures to describe type and severity of cleft	Observe, examine and describe post cleft repair  Non-speech tasks such as, smile, blowing a kiss  Imitation of tongue movements	Observe and describe repaired cleft Non-speech and speech tasks such as repeating mama Repeating syllables to observe tongue functions (ta, ka) Mirror test and other methods to test nasal emissions	Observe, examine and describe repaired cleft (adequacy of repair, if a palatal fistula is present, velopharyngeal closure)  Non-speech and speech tasks as for toddlers including tasks such as phonation of vowels for voice quality and respiration  Mirror test and other methods to test nasal emissions	

Sources: (Kummer, 2008: 319-342; Peterson-Falzone et al., 2006: 104; Peterson-Falzone et al., 2010: 280-284; Shprintzen & Bardach, 1995: 212-215; Watson et al., 2001: 202).

It is important to solicit a child's cooperation to elicit non-speech and speech tasks of specific significance to children with CL/P. Orofacial examinations are possible and necessary at the toddler/preschool stages when secondary surgical decisions need to be made based on an accurate diagnosis of velopharyngeal closure.



#### 3.5.8 Speech production assessment

Objective and accurate assessment of speech production is crucial in determining treatment outcomes. Currently, the best practice recommendation for speech evaluation and velopharyngeal functioning in children with CL/P is a thorough auditory-perceptual evaluation and use of instrumental techniques namely, videofluroscopy, nasopharyngoscopy and electropalatography (Kuehn & Moller, 2000: 352; Peterson-Falzone et al., 2010: 272; Watson et al., 2001: 265).

#### 3.5.8.1 Perceptual speech assessment procedures

Speech production assessment at the *infant stage* includes assessment of the phonetic repertoire through parental reports of the infant's vocalizations and canonical babbling. At the *toddler stage* frequency and diversity of consonant production is assessed. In addition to parent reports speech productions are elicited during play-based assessment (Peterson-Falzone et al., 2010: 267). Audio and video recordings and analysing transcriptions of the babbling and vocalisations are recommended methods used to complement the information obtained from the parents regarding the babbling and vocalisations of the infant with CL/P (Sell, 2005: 107). At the *preschool stage*, comprehensive phonetic and phonologic assessments using appropriate assessment instruments such as articulation tests, to elicit a speech sample, are recommended (Watson et al., 2001: 202). Perceptual speech assessment is the most commonly used procedure as listening is the best indicator of whether or not there is a speech problem (Henningsson et al., 2008: 1; Peterson-Falzone et al., 2010: 285). The perceptual speech assessment of preschool



children may be conducted using a standardized articulation test to identify the types of errors for example the commercially available The Goldman-Fristoe Test of Articulation (2000) or articulation tests specifically developed for the cleft population such as the Great Ormond Street Hospital Speech Assessment (GOS.SP.ASS'98, Sell et al., 1999). Controversies persist regarding how to measure and report speech characteristics due to the variations among the various systems used to collect and analyze perceptual data related to speech (Hutters & Henningsson, 2004: 544; John et al., 2005: 273; Kuehn & Moller, 2000: 348; Lohmander-Agerskov & Olsson 2004: 64; Sell et al, 1999: 117; Sell, 2005: 113; Whitehill, 2002: 53; Wyatt et al., 1996: 147). A need to standardize speech measurement procedures across cultures and languages has been identified so that meaningful comparisons of treatment outcomes can be made internationally through multicentre studies to improve the standard of cleft care globally (Henningsson et al. 2008: 1-17). Selected examples of perceptual speech assessment instruments that measure the cleft type speech characteristics are presented in Table 3.7.



**TABLE 3.7** Examples of perceptual speech assessment instruments and procedures

<b>Instrument and Procedure</b>	Source	Description	
GOS.SP.ASS.'98 (revised) Perceptual standardized screening procedure	Sell et al. (1999)	A comprehensive speech assessment protocol used for both clinical and research purposes. Nasal resonance, emission, turbulence and grimace are rated in terms of severity and consistency, according to defined categories. Articulation of consonants is analysed in terms of cleft type characteristics (CTCs) for example: active (dentalisations, palatalisation) and passive (nasal realizations, absent pressure consonants) CTCs.  It includes a systematic approach to an oral examination, the mirror test and description of the visual appearance of speech.	
Cleft Audit Protocol for Speech-Augmented (CAPS-A)	John et al., (2006)	Speech outcomes for intelligibility, voice, resonance, nasal air flow, consonant production and cleft type speech characteristics are judged by speech-language therapists based on an elicited speech sample.	
Universal parameters for reporting speech outcomes in individuals with CL/P	Henningsson et al., (2008)	A set of five universal speech parameters have been devised for reporting. Hypernasality, hyponasality, audible nasal emissions, consonant errors and voice disorders. Two global parameters namely speech understandability and speech acceptability have also been included.	

In order to assess the speech of a child with CL/P using any of the above procedures, a speech sample elicited with the use of standardized speech elicitation materials and a spontaneous speech sample is recommended (Henningsson et al., 2008: 9; Lohmander-Agerskov & Olsson 2004: 64; Sell, 2005: 106-107). The assessor's knowledge of the target language and its phonetic characteristics is also an important factor in assessing the phonological development of young children with CL/P (Brondsted et al., 1994: 110). The complexities of standardization and reliability checks should be taken into account during elicitation of speech samples from young children. The universal parameters in reporting speech (Henningsson et al., 2008: 5) may be



used as guideline to prepare language specific speech elicitation materials and ensure consistency in types of sounds sampled across languages. The elicited speech sample needs to be analysed to identify and describe cleft speech characteristics (e.g. consonant errors, nasal emissions/turbulence and hypernasality). Perceptual rating scales of resonance for speech assessment of young children with CL/P have been widely studied and validated as reliable measures (Hirschberg & Van Denmark, 1997: 161; Lohmander-Agerskov & Olsson, 2004: 65; Sell, 2005: 103).

The use of digital audio and video recordings of speech is recommended for speech analysis as high fidelity recordings that are amenable to computer storage and playback increase reliability of inter and intra-rater speech analysis (Sell, 2005: 107; Shriberg et al., 2005: 356). Low-tech procedures such as the mirror test and nostril-pinching tests can be used to evaluate the child's ability to achieve velopharyngeal closure and to determine whether nasal emissions and/or hypernasality are present (Kummer, 2008: 332). Repetition of syllables with pressure-sensitive phonemes, and high and low vowels (papapapa; pipipipi; sasasasa; sisisisi) are adequate speech samples for these low-tech speech assessments that can be elicited from very young children (Kummer, 2008: 332-333). However, Peterson-Falzone et al. (2006: 42) argued that the reliability and validity of these methods are doubtful and clinicians often rely on an 'objective' backup for their judgements. Non-instrumental test procedures are based on auditory-perception of the therapist to judge and analyze the speech of the patient. This can be problematic in terms of reliability, validity of the measurement procedures and when comparisons need to be made from one centre to another (Shaw, 2004: 239).



Instrumental speech assessment procedures provide supplementary information to perceptual speech measure of resonance and guide recommendations for the specific type of treatment, especially surgery (Kuehn & Moller, 2000: 364; Kuehn & Henne, 2003: 106; Peterson-Falzone et al., 2006: 41).

#### 3.5.8.2 Instrumental speech assessment procedures

Instrumental speech assessment evaluates what cannot be observed during an oral examination and also quantifies and documents velopharyngeal closure. The most frequently reported instrumental assessments and procedures to assess speech and velopharyngeal function in preschool age children (Kuehn & Moller, 2000: 365; Lohmander-Agerskov & Olsson, 2004: 68) are:

- Videoflouroscopy: radiographic images of the velopharyngeal closure as the individual repeats a variety of phonemes in connected speech are recorded on video tape or digitally. However, the risk of radiation, although minimal does exist.
- Naspharyngoscopy/videoendoscopy: a fibreoptic nasopharyngoscope can be used for a clear view of the velum, pharyngeal walls and size, shape and site of any velopharyngeal gap. The procedure requires the individual to repeat a standard list of sentences and velopharyngeal function during connected speech that can be observed and recorded.
- Nasometry: acoustic energy is measured using a microphone and micro-computer software to obtain objective data of nasal resonance for speech analysis. The



individual reads a passage or repeats a standard list of sentences; the nasalance scores are compared to standardised norms.

(Kummer, 2008: 377; Peterson-Falzone et al., 2010: 292-314; Shprintzen, 2004: 572).

Management decisions about surgical procedure, prosthetic management and speech therapy intervention for the perceived speech abnormality need to be made based on both perceptual speech analysis and instrumental assessment of the velopharyngeal closure (Peterson-Falzone et al., 2006: 42-43; Shprintzen, 2004: 588;).

## 3.5.9 Developmental screening

Annual monitoring of development by a cleft palate team is recommended as best practice (ACPA, 2007: 12; Scherer & Kaiser, 2007: 12; Wyszynski, 2001: 304) as developmental delay is a common feature of children with CL/P, especially in syndromic cases. Developmental screening is a pivotal need of young children with CL/P and serves as an entry point for children to enter the ECI process (Kritzinger, 2000: 44).

There is a wide range of instruments available for developmental screening that use a combination of direct assessment with checklists, observations, and parental interview (Guralnick, 2005: 78). The views and perceptions of teachers, psychologists and others who have contact with the child may also be obtained to complement the speech-language therapists' observations. Speech-language therapists and audiologists may use developmental screening



instruments to identify children who may require further assessments by other professionals for example, the paediatrician, psychologist and occupational therapist.

**TABLE 3.8** Developmental screening procedures and instruments

Procedure &	Stages						
Instrument	Neonatal	Infancy	Toddlerhood	Preschool stage			
Case history	Parent interview detailed prenatal, natal and family history	Motor developmental history (milestones such as head holding, sitting, walking)		Motor and cognitive developmental history and adaptation to school environment			
Observations	Reflexes, and screening for presence of congenital anomalies	Gross and fine motor skills Cognitive, personal social behaviour Self help skills Play observations: exploratory, symbolic		Psychosocial, cognitive, social interactional development			
Examples of instruments	-	Use of milestone developmental s For example Des Scales of Infant Battelle develop inventory Minnesota Child Inventory	creening tools nver II, Bayley Development II, mental	Developmental screening of learning problems, school related issues, and psychosocial functioning  Minnesota Child Development Inventory			

Sources: (Blackman, 1995: 82-84; Shonkoff & Meisels, 2000: 244; Wyszynski, 2002: 304-305).

Speech-language therapists and audiologists have to be knowledgeable and resourceful in selecting the most appropriate assessment procedures and instruments. They may need to develop new assessment instruments or adapt and even translate existing instruments to suit the local context and compensate for the lack of certain services and a team approach. The



challenges posed to conducting communication assessments in developing countries are discussed forthwith.

# 3.6 CHALLENGES TO COMMUNICATION ASSESSMENT IN DEVELOPING COUNTRIES AND POSSIBLE SOLUTIONS

The quality of cleft care provision is dependent on the existing health care service and developing countries lag behind in cleft care services, primarily because cleft care is not a health priority (Mars et al., 2008: xi). Many developing countries, despite the challenges to cleft care are striving to provide improved services to all individuals with CL/P (WHO, 2002) through local capacity building and collaborating with international organisations. The interdisciplinary team-based approach allows the various professionals to conduct assessments from their specialized perspectives and construct a collaborative coordinated intervention plan based on these assessments can then be implemented (ACPA, 2007: 5; Kummer, 2008: 299; Mars et al., 2008: 15).

Some of the challenges that speech-language therapists and audiologists in developing countries may face in conducting assessments of young children with CL/P possible solutions are presented in Figure 3.4.



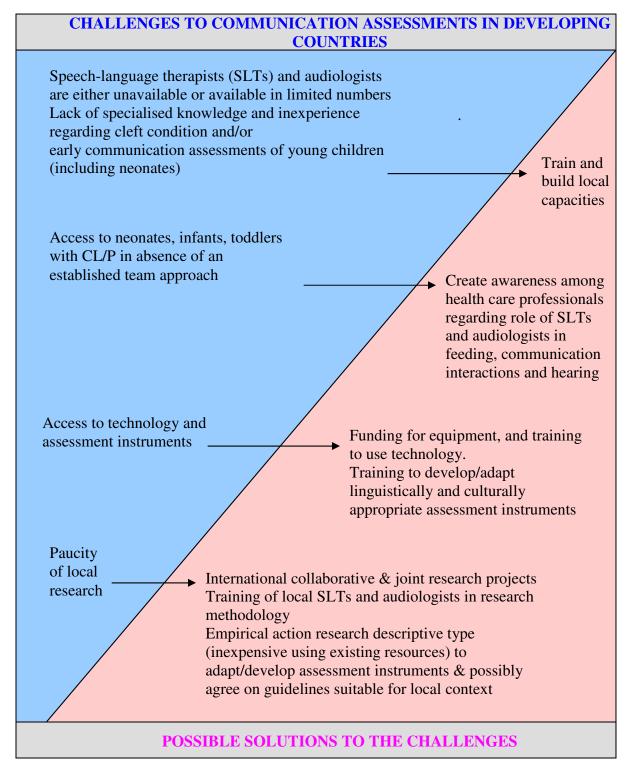


FIGURE 3.2: Challenges to communication assessments in developing countries and possible solutions



(Based on: Bzoch, 2004: 572; D'Antonio, 2002: 1; Kuehn & Henne, 2003: 365; Mars et al.,

2008: 198; Prathanee et al., 2006: 501; Sell, 2007: 17; Winterton 1998: 112; WHO, 2001b).

Many speech-language therapists and audiologists in developing countries may be unfamiliar with the concepts and techniques involved in the care of a child with craniofacial anomaly and CL/P (Kuehn & Henne, 2003; Grames, 2008: 10-12; Pannbacker, 2004; Vallino-Napoli et al., 2008: 374). Their knowledge and experiences in early communication intervention including assessment of neonates, infants and toddlers may also be limited (Mroz & Hall, 2003: 125). Training and local capacity building in speech-language therapy for cleft care has been strongly advocated by the Smile Train (D' Antonio, 2002), and Sell, (2007: 17).

The recommended interdisciplinary team based approach to conduct effective, efficient assessments and coordinate interventions through effective referral systems (ACPA, 2007) may also be inadequately applied in many developing countries (Mars et al., 2008: 192). The lack of a coordinated interdisciplinary team-based approach to assessment due to a limited number of professionals and resources implies that professionals cannot focus on specific areas. Health care professionals involved in cleft care may not be aware of the role of speech-language therapists and audiologists in early communication intervention of young children with CL/P. A possible solution to this problem is to create awareness regarding the benefits of ECI by speech-language therapists and audiologists from neonatal stage of a child with CL/P.

Speech-language therapists and audiologists in developing countries often do not have access to an assessment instrument that is contextually appropriate and applicable (D'Antonio, 2002: 1). They may adapt published protocols informally to suit their local context but may not conduct



research to determine its applicability and acceptability. A newly developed assessment instrument should be validated as well, but validation against an existing 'gold standard' assessment instrument from a developed country may not be appropriate. The lack of assessment instruments, limited specialised knowledge and experience of the team members conducting assessments, may further complicate the assessments of young children with CL/P. Furthermore, objective measurements and technology (videofluroscopy, brain-stem evoked response audiometry) that improve the accuracy, validity, reliability and effectiveness of speech language therapy and audiology services may not be available in many developing countries. Some laudable efforts have been made through grants to acquire equipment and surgical supplies to improve overall hospital standards (Mars et al., 2008: 65) but these should be extended to instruments required by speech-language therapists and audiologists to conduct assessments using sophisticated technological instruments as well. A possible solution would be to develop a communication assessment instrument and to evaluate its applicability and acceptability for routine clinical use by the speech-language therapists and audiologists. As mentioned earlier a well validated tool may not find its use in clinical practice if it cannot be applied in the local setting or if it is not acceptable to the user.

In developing countries, local speech-language therapists and audiologists may require specialist input in cleft care through capacity building and research collaborations such as action research. This highlights the need for collaborative research between speech-language therapists and audiologists from developed and developing countries to adapt and develop appropriate assessment instruments and procedures (Trindade, 2006: 724; WHO, 2002: 31). Examples of such capacity building projects are the Sri Lanka Project (Wirt et al., 1990) and the Ethiopia



Project (Holmefjord & Berntsen, 2005). Collaborative research with developed countries that have assessment instruments and procedures in place for example the European cleft project, could assist and support speech-language therapists from developing countries to contribute local cultural and linguistic knowledge in adapting and developing appropriate assessments instruments.

In some contexts, although the core team members may be present, the lack of organisation of services to provide a coordinated team-based approach assessments with appropriate assessment instruments could result in a fragmented approach to assessments and interventions that are detrimental to quality cleft care. Therefore, collaborative research is a catalyst for action to develop, improve and build local capacities. This may be achieved by focusing on specific obstacles and improving resource use and availability (Walley et al., 2007: 424).

#### 3.7 CONCLUSION

Cleft teams in developed countries have established protocols and guidelines for best practice to ensure comprehensive, coordinated and quality cleft care. Management of young children with CL/P is best provided by regular, formal, interdisciplinary team assessments to monitor the child's development, and measure treatment outcomes in individuals with CL/P (ACPA, 2007: 5). Although best practice guidelines for assessments and management are accessible to all, the implementation of these is not universal. Certain developing contexts may be so unique and different that the guidelines may fail to encapsulate their local realities.



In developing countries, such as Mauritius, the implementation of best practice guidelines remains a challenge due to limited research, limited number of professionals to participate in the multidisciplinary team approach and the lack of appropriate tools for assessments of the children by the team members. Given the importance of communication development in young children, speech-language therapists and audiologists need to be resourceful and adopt diverse roles and responsibilities to apply the current best practice as a guiding framework to communication assessment. A framework for the development of a communication assessment protocol, that may be applicable in a developing country, is presented in Figure 3.3.

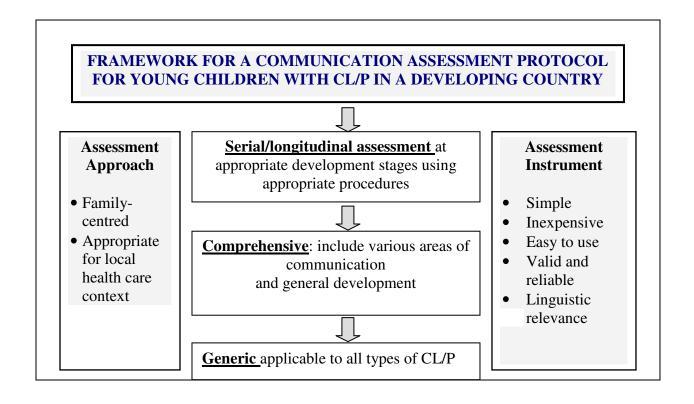


FIGURE 3.3 Framework for development of a Communication Assessment Protocol for young children with CL/P in a developing country



The proposed framework is adapted from available best practice guidelines for assessment of young children with CL/P and may be used to develop a comprehensive, holistic communication assessment protocol for clinical use by speech-language therapists and audiologists.

#### 3.8 SUMMARY

In this chapter, the recommendations on the areas of communication assessment and serial assessments according to developmental stages of young children with CL/P have been described. These recommendations are based on existing models of cleft care in developed countries. The developing countries face specific challenges for communication assessment, such as access to locally acceptable and applicable instrument. The challenges for assessment procedures were identified and possible solutions to meet these challenges were proposed.

A framework for the development of a generic and holistic communication assessment protocol of young children with CL/P was proposed. It provides the underpinnings for the empirical research conducted.



# CHAPTER 4:

# **METHODOLOGY**

The aim of this chapter is to describe the methodology used to conduct empirical research for developing a Communication Assessment Protocol and database for young children with cleft lip and/or palate in Mauritius.

#### 4.1 INTRODUCTION

The speech-language therapy and audiology services in Mauritius are not well developed. This is due to scarcity of resources and a lack of research facilities. There are only four therapists employed in the public health sector to serve a population of 1.2 million inhabitants. The therapists have heavy clinical workload and they use their clinical experience to assess and manage individuals with a variety of communication disorders across a wide age range without any structured protocol. Best clinical practice needs to integrate research evidence with clinical expertise and incorporate patient values (Johnson, 2006: 20). The importance of an evidence-based approach to clinical practice is well recognised for the management of communication disorders (Maxwell & Satake, 2006: 9).

In developed countries, the guidelines for assessment of speech-language and hearing of children with cleft lip and/or palate are based on evidence from extensive research (Bzoch, 2004; Kummer, 2001; Peterson-Falzone et al., 2010; Shprintzen & Bardach, 1995; Watson et al., 2001). However, it is not known whether the guidelines are appropriate for speech and language



assessments in less developed countries with limited resources and multilingual and multicultural populations. There is an unmet need to develop or adapt existing tools for assessment, especially in developing countries where such resources are rare (Carter et al., 2005: 385). Research into the assessment and treatment methods for communication disorders can strengthen the scientific and technological bases of service delivery (Hegde, 2003: 19; Johnson, 2006: 21). In this study, empirical research was conducted to develop a Communication Assessment Protocol, establish if the protocol is applicable and acceptable and initiate a database for children with CL/P in Mauritius.

#### 4.2 CONCEPTUAL FRAMEWORK

A conceptual framework maps the thought process of the researcher and helps to shape and guide how the research will be conducted (De Vos et al., 2005: 35). The literature review has shown that children with CL/P require a team approach to assessment and management. The recommendations for best care for children with CL/P suggest early intervention (from the neonatal stage) and longitudinal assessments to measure the outcome of treatment (ACPA, 2007: 24). Moreover, the ACPA (2007) recommends that the assessment protocol should also be sensitive to linguistic, cultural, ethnic, psychosocial, economic and physical factors that affect the dynamic relationship between the team and the family. However, in resource-limited developing countries, such as Mauritius, where a team approach to cleft care is not in place and no database exists on individuals with cleft, the speech-language therapists and audiologists have the challenging task to conduct appropriate assessments under resource constraints.



The conceptual model determines which questions are to be answered by the research, and how empirical procedures can be used to answer these questions (De Vos Strydom, Fouche, & Delport, 2005: 35). Research questions are often generated from a critical review of existing clinical practice (Reilly et al., 2004: 344). The following research questions arose from clinical experiences of a researcher managing children with CL/P in Mauritius.

• Is there a database available to access information on children with CL/P in Mauritius? What are the demographic characteristics of the children with CL/P in Mauritius?

In the absence of an appropriate database and a standard Communication Assessment Protocol and the need for compiling, a new protocol further questions that need answers:

- Which data needs to be stored in a database of children with CL/P in Mauritius?
- Which aspects of communication need to be assessed and at what ages?
- Is the Communication Assessment Protocol clinically applicable for assessment of young children with CL/P in Mauritius?
- Is the Communication Assessment Protocol acceptable to the speech-language therapists and audiologists in the Mauritian context?

Answering these questions required action research that focused on finding a solution to a local problem in a local setting. Action research is a small-scale intervention in the functioning of the real world and involving a close examination of its effects (Johnson, 1994: 116). The present study was conducted in a small developing country (Mauritius) with limited resources for the purposes of developing a tool for routine clinical use by speech-language therapists and audiologists. The research was conducted to describe the characteristics (demographic and clinical) of children with CL/P. An appropriate communication assessment protocol was



developed within the framework of international trends in cleft care (ACPA, 2007; Eurocran 2000; WHO 2002). A participatory action research approach was adopted (De Vos et al., 2005: 409; Leedy & Ormrod, 2005: 108; Maxwell & Satake, 2006: 13) for the development of the protocol. Participatory action research encourages a feeling of ownership of the project and motivates participants to action and change that continues after the research is completed (De Vos et al., 2005: 420). The speech-language therapists and audiologists from the public health sector in Mauritius participated to develop the Communication Assessment Protocol. This was followed by field evaluation of the protocol to determine applicability and acceptability of its use to the speech-language therapists and audiologists in their routine practice.

#### 4.3 RESEARCH AIM AND OBJECTIVES

The main aim of the study was to develop a Communication Assessment Protocol for young children with cleft lip and/or palate in Mauritius. The following objectives were set:

- To create an electronic database and document descriptive characteristics of children with CL/P in Mauritius
- To compile a Communication Assessment Protocol and evaluate its applicability
- To evaluate acceptability of the protocol in the local context.

#### 4.4 RESEARCH DESIGN AND RESEARCH PHASES

The research design refers to the general strategy for solving the research problem with a plan for data collection and data analysis (Leedy & Ormrod, 2005: 85). The assessment of



communication disorders in children with CL/P is a very complex phenomenon. Therefore a combination of quantitative and qualitative research methods was employed to answer the questions in the study. Participatory action research in this study was adopted for collaborative action to 'learn by doing' (De Vos et al., 2005: 410) and implement change to communication assessment of young children with CL/P. Some of the quantitative data were collected using questionnaires (face-to face interviews) with parents of the children with CL/P and review of hospital records, to obtain data for descriptive characteristics of the children. quantitative data collection instrument was a communication assessment protocol that was compiled from a review of existing assessment protocols from developed countries. Furthermore, to evaluate the applicability of the protocol the speech-language therapists and audiologists assessed the communication behaviours of children with CL/P using the newly compiled assessment instrument. Audio-visual recordings were made of the children's speech. Descriptive statistics (Maxwell & Satake, 2006: 280) were used for classifying, organising, and summarizing the data in terms of frequency counts, a convenient manner for numerically evaluating the attributes of the available data.

The qualitative research component in this study refers to in-depth interviews and focus group discussions (Hakim, 2000: 10) that were conducted with the speech-language therapists and audiologists to determine the acceptability of the protocol. Priority was given to quantitative data while qualitative results were used to assist in explaining and interpreting the findings of the primarily quantitative study. In this research study, a mixed methods research design (Creswell, 2003: 215), characterised by the collection and analysis of quantitative data followed by the collection and analysis of qualitative data, was adopted. Triangulation is common in mixed-



method designs in which both quantitative and qualitative data are collected to answer the research questions (Leedy & Ormrod, 2005: 99). Two types of triangulation (Denzin & Lincoln, 2000: 391) were applied in this research:

- Data triangulation: the use of a variety of data sources namely medical documents, parental reports and direct observations.
- Investigator triangulation: the use of several different researchers for gathering data.

The research objectives were achieved through planning and conducting research in the following three sequential phases, as depicted in Figure 4.1.

#### **Phase One**

Describing characteristics of children with CL/P and compiling an electronic database.

Quantitative data collection and analysis to describe the main characteristics of these children.

The results provided the framework for Phase Two of the study

# **Phase Two**

Compiling the Communication Assessment Instrument. Descriptive and contextual study (Leedy & Ormrod, 2005: 179) to evaluate the clinical applicability of the Communication Assessment Protocol.

#### **Phase Three**

Conducting a questionnaire survey and focus group discussion (Bloor, Frankland,

Thomas & Robson, 2001: 18) of speech-language therapists and audiologists to evaluate the acceptability of the protocol.

#### FIGURE 4.1 Research phases to develop the communication assessment protocol



A detailed description of the three phases is provided following the description of the study site and research ethics.

#### 4.5 CONTEXT OF THE STUDY

The island of Mauritius was the context of the current research project. Mauritius is a very small island in the Indian Ocean, shown in Figure 4.2.

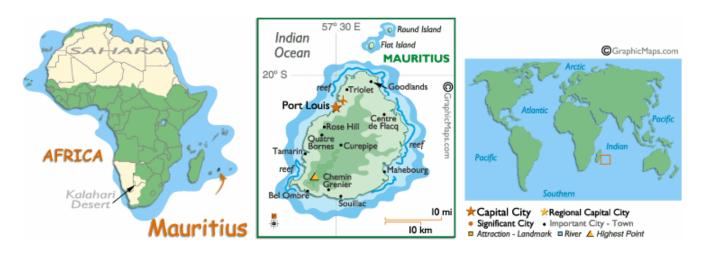


FIGURE 4.2 Context of the study: Mauritius

Mauritius is densely populated island with 1.2 million people living on a landmass of less than 1000 square kilometres (Central Statistics Office, 2003). The population is heterogeneous and composed of three ethnic groups namely, Asian, Caucasian and of African origin. The official language is English but French and a local dialect Creole are widely spoken. The Human Development Report (2004) published for the United Nations Development Programme (UNDP) ranked Mauritius as 16<sup>th</sup> amongst developing countries and classified it as a country with "medium human development". Primary education is free and compulsory; therefore, literacy levels are high in Mauritius. In 2002, 84.3 % of the population was literate. Skilled persons

attend to 99% of births, the fertility rate is 1.9 (2000-2005) and the public sector spends 2% of GDP on health; an indicator of the level of resources attributed to the provision of health services. Despite the limited resources, health care provision in the public sector in Mauritius is free. The National Health Service is well structured and public health services are accessible to the public at five regional hospitals across the island.

- Victoria Regional Hospital (VH) and a specialized ENT Centre situated in the central part of the island.
- Sir Seewoosagar Ramgoolam National Hospital (SSRNH) situated in the northern region.
- Dr. Jeetoo Hospital (Jeetoo) situated in the capital city, Port Louis.
- Jawaharlal Nehru Hospital (JNH) situated in the southern region.
- Flacq Regional Hospital situated in the eastern region.

At the time of the study, there was only one plastic surgeon in the public health sector and four speech-language therapists and audiologists. The plastic surgery clinic is centralized at the Victoria Regional Hospital and surgical repairs of clefts are performed at this hospital. Victoria hospital was the location for conducting this study. The speech-language therapy and audiology services are combined and provided at four of the five regional hospitals. The Victoria Regional Hospital has a specialized centre that provides ENT and speech-language therapy and audiology services to all referred cases including children with CL/P. The other professionals required in the management of children with CL/P namely orthodontists, paediatricians, nutritionists, psychologists are available and their services are provided at each of the five different regional hospitals. However, the multidisciplinary team approach at one centre is not available to children with CL/P and their families.



#### 4.6 RESEARCH ETHICS

Ethical principles in research are important whenever human beings are the focus of a study and particularly when vulnerable groups such as children are the research participants (Creswell, 2003: 64; Leedy & Ormrod, 2005: 101). As the research study included a vulnerable group (children with CL/P), the researcher was particularly sensitive to observing the principles of research ethics. The following three ethical principles and guidelines (Morgan, Gliner & Harmon, 2006: 19-23) directed the researcher's actions.

- Respect for Persons: Participants should be treated as autonomous individuals and vulnerable groups such as children should be protected.
- Beneficence: A good outcome should be maximized for the participants as well as science and humanity. Researchers should not harm the participants.
- Justice: Research should not be exploitative and selection of participants should be justified.

The principle of respect for three sets of participants (children with CL/P, their parents and the speech-language therapists and audiologists) was applied in the current study as follows:

Informed consent - The adult participants were provided information regarding the research procedure purpose and benefits (Leedy & Ormrod, 2005: 101). The information was provided to parents of the children in a clear intelligible written language and explained verbally. For adult participants a written signed consent was obtained in the presence of a neutral witness. However, for young children as participants, parental consent was obtained and when possible assent was elicited from the children before administering the communication assessment. The



consent was voluntary (Appendices III and IV) and no monetary compensation was offered as an incentive to the participants (Morgan et al., 2006: 20).

Withdrawal - The participants had the right to withdraw at any time they wished to and were assured that this would not be detrimental to them (Leedy & Ormrod, 2005: 102).

Anonymity and confidentiality - Since the aim of this research project was to develop a Communication Assessment Protocol and test its clinical applicability, face-to-face interviews and observations of the participants were also necessary. The individual's identity was confidential when reporting the results. Babbie (2001: 472) pointed out that 'anonymity' cannot be guaranteed when interviews are planned in a research project. The names of children as participants appeared on the record forms only to aid the researcher in compiling the correct individual profiles, and to provide parents or caregivers with appropriate feedback on their children. The allocated numbers were used for statistical analysis and publication. The same would apply to future publications to ensure confidentiality.

The principle of beneficence requires that the assessment procedure does not involve any risk of physical harm to the children with CL/P. Rapport was established with the children before proceeding with the communication assessment, and parents were present throughout the communication assessment. The children felt safe during the assessment procedures.

The research ethics principle of justice is reflected in the selection of participants namely the speech-language therapists and audiologists, children with CL/P and their families. All children with CL/P in Mauritius had an equal opportunity to be included in the study. Researchers are ethically obliged to ensure that they are competent and adequately skilled to undertake the



investigations (De Vos et al., 2005: 69). Only qualified speech-language therapists and audiologists conducted the research procedures. Researchers also have an ethical obligation to colleagues in the scientific community to report the results in an honest manner (Babbie, 2001: 475). Due acknowledgements were given to sources consulted and people who collaborated in this research.

The following sections provide a description of the three phases in which the research was carried out.

## 4.7 PHASE ONE

The objective of Phase One, the participants involved, data collected and analysis procedures employed are described in this section.

## 4.7.1 Objective of Phase One

The objective of Phase One was to describe demographic and clinical characteristics of young children (0-6 years) with CL/P and to create a database. Figure 4.3 illustrates the steps taken to achieve this objective.



# **PHASE ONE**

#### **Obtained ethical clearance from:**

Ministry of Health, Mauritius and
Research Proposal and Ethics Committee, Faculty of Humanities,
University of Pretoria

#### **Selected participants**

Children with CL/P

Parents of selected children with CL/P

Speech-language therapists & audiologists

Developed the questionnaire as data collection instrument

Conducted parental interviews and gathered data

Analysed, interpreted the data to describe characteristics of

children with CL/P, and created a database

FIGURE 4.3 Steps taken to describe the characteristics of the children with CL/P in Mauritius (Phase One)

Ethical clearance was obtained from both the Research Proposal and Ethics Committee, Faculty of Humanities, University of Pretoria, and the Ministry of Health, Mauritius to conduct research and develop a Communication Assessment Protocol for young children with CL/P in Mauritius prior to the data collection (refer to Appendices I and II).

# 4.7.2 Phase One participants

The participants of Phase One consisted of three groups:



- Children (0-72 months) with CL/P
- Parents of the selected children
- Speech-language therapists and audiologists, employed by the Ministry of Health,
   Mauritius collaborated in the participatory action research.

The sampling method, selection criteria, selection procedure and description of each group of participants in Phase One are described below.

# 4.7.2.1 Children with cleft lip and/or palate

The target population in this study was children in the age range 0-72 months with CL/P in Mauritius.

# Sampling method

The incidence of CL/P in Mauritius has been reported as 1 in every 1500 births (Sevanandee, 2004). The birth rate for the past five years in Mauritius has remained constant and is approximately 18,500 live births annually as reported by the Health Statistics Unit, Ministry of Health. Therefore, the number of children with CL/P in Mauritius is estimated to be low. The incidence of CL/P varies in different parts of the world. The average birth incidence of CL/P in the western world is reported as 1 in every 700 live births to 1 in every 1000 births (WHO, 2002: 4). As the available participant data pools in Mauritius are limited a consecutive sampling method was used. Consecutive sampling is a type of non-probability sampling technique that involves selecting all individuals who agree to participate, provided they meet pre-established criteria (Maxwell & Satake, 2006: 96).

#### • Selection criteria



The following criteria were established for selection of the children as participants:

# - Cleft lip and/or palate

The children as participants were required to have been born with a cleft lip and or cleft palate. Any one of the manifestations of cleft for example: unilateral or bilateral clefts of the lip, incomplete or complete clefts of the palate, overt or submucous clefts (Peterson-Falzone et al., 2010: 10-18) were included as this congenital anomaly was the focus of the current study.

#### - Age range 0-72 months

Children had to be between the ages of 0-72 months as the aim of the study was to develop a Communication Assessment Protocol for young children with CL/P. It is during these early years that the primary surgeries to repair the clefts are performed. Communication assessments in individuals with CL/P begin in infancy (Bzoch 2004: 23; Peterson-Falzone et al., 2010: 2). Potential communication difficulties can be identified and preventive work undertaken to promote more normal patterns of speech-language development (Watson et al., 2001: 191). Therefore, the period from birth to 6 years is critical for young children with CL/P and their families.

#### - Registered as patients at the Victoria Regional Hospital

Children with CL/P had to be registered at the Victoria Regional Hospital. Children born with CL/P from any part of the island of Mauritius are referred to the centralized plastic surgery unit at the Victoria Regional Hospital for plastic surgery. The records available here can be considered as the Mauritian database for children born with clefts. All children selected were required to be registered at this public hospital, as the purpose of this research was to develop a Communication Assessment Protocol for use in the public health sector of Mauritius. Children



with CL/P from the private sector were not included in the study as the context of this study was the public health sector.

#### - Syndromes and associated anomalies

Clefts are generally multi-factorial in origin and children with clefts may also have syndromes and associated anomalies with severe communication disorders (Shprintzen & Bardach, 1995:16). Research studies on clefts generally do not group multi-anomaly disorders that include clefts with isolated cleft cases (Peterson-Falzone et al., 2010: 57) because the symptoms and nature of problems for the two groups are variables that are considered to confound results and render conclusions to be questionable. In planning the current study, the researcher was cognisant of this methodological issue but included all children with CL/P in the public health care system in Mauritius. This implied that the study included children with syndromes, sequences and associated anomalies. This decision was based on the aim of the research namely to develop a national database for Mauritius that would include all children with clefts and to ensure the applicability of the communication assessment protocol across the spectrum of cases involving clefts. Race, gender, cultural family background, socio-economic status, educational background of parents were not considered as delimiting factors as the objective of the study was to describe the characteristics of children with CL/P.

# • Selection procedure

The selection procedure for children with CL/P as participants was as follows:

- Permission was obtained verbally from the records officer to access the medical files for the purpose of selection of children with CL/P for research. Ethical clearance had been obtained from the Ministry of Health (Appendix I).

- A search from the hospital records of Victoria Regional Hospital (plastic surgery service is centralized) was made and a list of registered children with CL/P was compiled.
- The medical files of the selected children were reviewed and children who met the above selection criteria were identified. The contact details of the children with CL/P were obtained from their hospital records.
- A list was compiled which consisted of the name, date of birth, contact details (namely address and telephone number) and file number for each child. A total of 125 case records were reviewed. The sample frame of children is described in Table 4.1
- Parents of 88 children from the 91 contacted agreed to participate in the study.

TABLE 4.1 Sample frame of children with CL/P

All children registered at Victoria Regional Hospital with CL/P selected from the medical				
records				
Target population	125 children born as from January 2000 in the age range of 0-6 years			
	with CL/P			
Of these 125 medical	- 16 records did not have contact details; telephone number &			
records studied	address was unknown.			
	- 11 children were over 6 years (age instead of date of birth was			
	registered)			
	- 5 files were duplicates			
	- 2 of these children had passed away			
	Therefore 91 children were selected for the study.			
	The parents of 88 children agreed to participate in the study.			

Although the total number of children was 88, only 80 participated in the main study as eight were selected for the pilot study.

• Description of the children as participants



The selected children were from various regions of Mauritius. The distribution of children with CL/P according to region where they reside and receive the speech-language therapy and by age group: birth to younger than 36 months and 36-72 months is depicted in Figure 4.4.

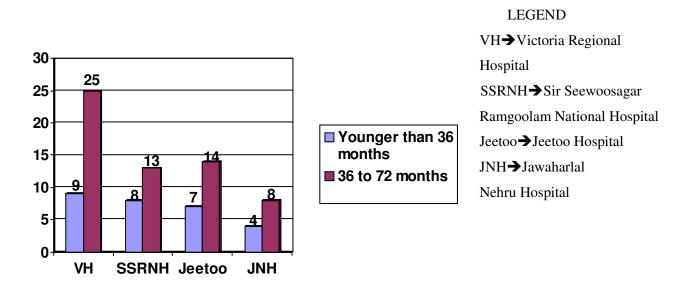


FIGURE 4.4 Age distribution of children as participants

The majority of the children (60/88) were in the age group of 36-72 months. Only 28 children were younger than 36 months. As mentioned previously, the public health sector has five regional hospitals but speech-language therapy and audiology services are available in only four of these regional hospitals. Therefore, the children residing in the east part of the island access the service at Sir Seewoosagar Ramgoolam National Hospital (SSRNH; north region).

Cleft lip occurred only amongst 13.6% of the children included in the sample, whereas cleft palate only, occurred amongst 42% (refer to Table 4.2). Cleft lip and palate occurred in 42% of the children. The proportion of *cleft type* as estimated in the literature is 25% cleft lip, 25% cleft palate alone and 50% cleft lip and palate (Peterson-Falzone et al., 2010: 24). The sample in this study does not reflect the reported distribution and further research will be required to confirm these results. As only two children had submucous cleft type in the sample it is hypothesised

that an estimate of the frequency of submucous cleft palate may be artificially low. Peterson-Falzone et al. (2010: 18) also report artificially low estimates of children with submucous cleft palates, as many submucous clefts remain undetected. It is possible that submucous type cleft palates are not detected at an early age.

**TABLE 4.2** Characteristics of children with respect to cleft types

TYPE OF CLEFT / AGE GROUP	Cleft lip	Cleft palate	Cleft lip and Palate	Submucous cleft palate
Younger than 36 months	6	11	11	0
36-72 months	6	26	26	2
Total N=88	12 (13.6%)	37 (42%)	37 (42%)	2 (2.4%)

In the sample, 60% were female and 40% were male. The frequency of cleft palate only was also higher. The *gender distribution* reported in literature is variable depending on the racial group and type of clefts (Peterson-Falzone et al., 2010: 24). Overall cleft lip with or without cleft palate are more frequent in males and cleft palate only are more frequent among females (Wyszynski, 2002: 136).

It is important to distinguish between syndromic and nonsyndromic CL/P for determining management and recurrence risks for families (Wyszynski, 2002: 47). The distribution of the children in the sample, according to presence of syndromes is illustrated in Figure 4.5.

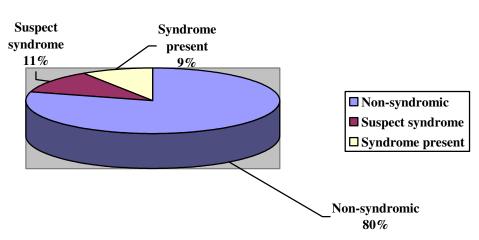


FIGURE 4.5 Presence of syndromes in the children as participants

Nonsyndromic CL/P has been reported between 70% and 80% of all cases (Wyszynski, 2002: 48). Shprintzen and Bardach (1995: 34) reported that more than half the children with clefts had a recognisable syndrome, sequence or associations and identifying the possible syndrome leads to better patient care. The local data indicate a possible under-identification of syndromes amongst these children; a possible reason is that in Mauritius the services of geneticists within the public health sector are not available. Identifying the presence of a syndrome is important for management of the children with CL/P.

#### 4.7.2.2 Parents of the children as respondents

The participation of the parents was necessary to obtain the essential background information from them about their child with CL/P and their perceptions regarding the communication ability of the child. Parents are considered partners in early intervention as language develops in children's larger familial contexts through meaningful and reciprocal engagement (Bagnato et al., 1997: 52; Blackman, 1995: 64; Golding-Kushner, 2001:35).



## • Sampling method for parents as respondents

A convenience sampling method (Maxwell & Satake, 2006: 96) was used to select parents as respondents. All parents, whose children had been selected and agreed to participate, were included.

## • Selection criteria for parents as respondents

The following criteria were established for selection of the parents as respondents in Phase One of the study:

# - Biological or adoptive parents

The adults selected as participants were required to be the biological or adoptive parents of the children with CL/P. Parents are the most important sources of information when describing child characteristics (Rossetti, 2001: 94).

- Parents of children with CL/P registered at the Victoria Regional Hospital

All the parents whose children met the selection criteria for the research were chosen as respondents in the study.

- Selection procedure of the parents as respondents
- -An information sheet regarding the study was provided to parents and their voluntary informed consent to participate along-with their child in the study was obtained (refer to Appendix III).
- Description of the parents as respondents

Parents of the eighty children selected for the main study, as respondents were described according to diverse characteristics such as their marital status (Figure 4.6) and educational levels (Figure 4.7).

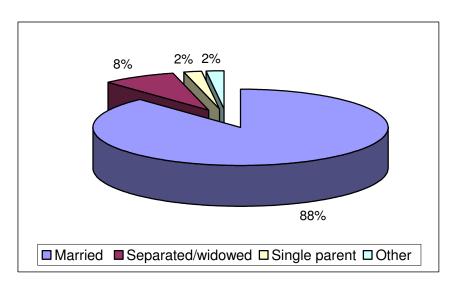


FIGURE 4.6 Marital statuses of the biological parents of children with CL/P

The majority of the parents were married and living together indicating that children came from stable families. The category-'other'- included couples living together (Figure 4.6). The evidence for genetic disposition to CL/P comes from family and twin studies (Watson et al., 2001: 88). Respondents were questioned regarding type of marriage as consanguineous marriages are documented as a high risk factor for birth of a child with congenital anomalies (Watson et al., 2001: 88). 97.5% of the marriages did not have any history of consanguinity. Only two marriages were consanguineous. The majority of the participating parents had obtained secondary education (Figure 4.7).

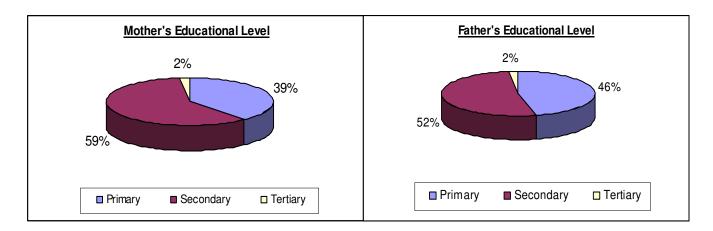


FIGURE 4.7 Highest educational qualifications of the parents

According to Shonkoff and Meisels (2000) higher educational levels enable the parents to be literate, self-supporting and parental educational levels are important in early intervention.

## 4.7.2.3 Speech-language therapists and audiologists as participants

In this participatory action research study, the speech-language therapists and audiologists were participants in all three phases of the research.

• Sampling method for speech-language therapists and audiologists

Convenience sampling as an all-inclusive criterion was applied in selection of the speech-language therapists and audiologists (Maxwell & Satake, 2006: 96). The available pool of participants was very small. At the time of the study, the Ministry of Health, Mauritius employed only four speech-language therapists and audiologists (including the researcher). Therefore, all were included provided they met the selection criteria and were willing to participate in the study.

• Selection criteria for speech-language therapists and audiologists



The following criteria were established for selection of the speech-language therapists and audiologists as participants:

#### - Qualifications

The speech-language therapists and audiologists were required to have at least an undergraduate degree in Speech-Language Therapy and/or Audiology, as they were required to perform communication assessments on the child participants and interviews with the parents of the children (ASHA, 2001: 1-25). Professional training would equip the participants to participate effectively in the research.

#### - Employment context

As the context of the study was the public health sector, the speech-language therapists and audiologists had to be employed by the Ministry of Health at the time the study was conducted. In routine clinical practice, speech-language therapists and audiologists in the public health sector are required to manage children with clefts for communication difficulties. Thus, they have experience in the management of these children and are familiar with the public health sector.

#### - Language proficiency

The speech-language therapists and audiologists were required to be proficient in the local language, Creole, and the other languages commonly spoken in Mauritius namely French and English, as they were required to complete the face-to-face questionnaire addressed to the parents and conduct assessments of the children with CL/P in the child's first language.

- Selection procedure for speech-language therapists and audiologists
- Permission was obtained from the Regional Health Directors for the speech-language therapists and audiologists posted in their regions to participate in the study.

- The three speech-language therapists and audiologists were invited for a meeting at the speech-language therapy unit, ENT centre of Victoria Regional Hospital and provided information regarding the research aim and objectives. Their voluntary informed consent to participate in the study was obtained (Appendix IV). The response rate was 100% as all the speech-language therapists and audiologists agreed to participate in the study.
  - Description of the speech-language therapists and audiologists as participants (Table 4.3)

**TABLE 4.3** Description of speech-language therapists and audiologists

Participants	Work Context	Years of experience	Gender and Age	Qualifications
Participant 1 (the principal researcher)	ENT/ Victoria Hospital (VH) in the central region)	23 years	F/ 47 yrs	M. Communication Pathology. Registered for D. Phil Communication Pathology degree
Participant 2	Sir Seewoosagar Ramgoolam hospital (SSRNH) in the north	2 years	F/ 26 yrs	B.Sc. Speech therapy & Audiology).
Participant 3	Dr. Jeetoo hospital (JH) the capital city hospital	7 years	F/ 30 yrs	M.Sc. Speech- Language Pathology
Participant 4	Jawaharlal Nehru hospital (JNH) in the south	7 years	F/ 29 yrs	B.Sc. Audiology & Speech-Language Pathology

The speech-language therapists and audiologists were female professionals employed by the Ministry of Health and worked at the four regional hospitals.

#### 4.7.3 Phase One materials

Materials for data collection tools in Phase One included hospital medical records and a face-to face questionnaire survey.



#### 4.7.3.1 Hospital medical records

The hospital records include demographic information such as name, gender, date of birth/age and religion of the child. The plastic surgeon's notes such as cleft type, reviews, dates of operations and the operative notes are also available in the hospital medical records. The information was used to prepare a data collection sheet that included the following information: code number, gender, name, contact number, date of birth, age group of the child, type of cleft, whether any syndrome was present, the regional hospital according to residence of the child, date of assessment and the therapist who would conduct the assessment.

#### 4.7.3.2 Interview schedule

An interview schedule (De Vos et al., 2005: 296; Neuman, 2000: 250) as data collection instrument was developed to gather and document information to describe the characteristics of the group of children with CL/P selected to participate in this study. An interview schedule has many advantages namely (De Vos et al., 2005: 299; Leedy & Ormrod, 2005: 185):

- Face-to-face interviews enhance response rate.
- The researcher can elicit specific information to meet the aims of the study.
- Open-ended questions can be added to allow respondents to express their specific concerns.
- Reading and writing skills of the respondents are not a concern as the interviewer completes the interview schedule.



The disadvantages of interview schedules are that they are time consuming and can be expensive (Leedy & Ormrod, 2005: 185). In this study, an interview schedule was deemed suitable as four speech-language therapists and audiologists had to interview 88 parent respondents.

The questionnaire included mainly closed-ended questions that were easy to answer, code, score and reduced subjective bias during the interview. It was based on the recommendations of the WHO (2001 b) 'Global Registry and Database on Craniofacial Anomalies'. The interview development of the interview schedule is described in Table 4.4 and the schedule is provided as Appendix V.



**TABLE 4.4** Development and description of the interview schedule

	INTERVIEW SCHEDULE PHASE ONE			
Sections	TYPE OF INFORMATION	OBJECTIVES AND QUESTIONS INCLUDED		
A (A1 to A4)	Biographical information	To create a record of children with CL/P. Questions were included on demographic characteristics of the child: name, gender, date of birth and address (CRANE 2000; WHO 2002: 140).		
B (B1 to B6)	Family background	To describe the background information relevant for description of the characteristics of the children with CL/P. Questions included the marital status of the parents, parental ages and educational background. Also information regarding family structure, number of siblings, and position of the child with CL/P was gathered. Questions pertaining to any history of consanguinity or family history of CL/P were also probed (Peterson-Falzone et al., 2010: 25). Questions regarding the main languages spoken at home and the most commonly spoken language were also asked. Cultural and linguistic sensitivity is recommended (ACPA 2007: 6; Eurocran Speech Project 2000) during communication assessment.		
C (C1 to C6)	Birth history	To describe the characteristics of children with CL/P. Questions pertaining to prenatal and peri-natal conditions of the mother and child were included. Information regarding presence of any syndrome or suspicion of a syndrome was also sought. The etiological heterogeneity of cleft condition includes antenatal factors, genetic factors and environmental conditions (Shprintzen & Bardach, 1995: 7; Watson et al., 2001: 10). The birth weight of the child was also noted as children born premature are at risk for other anomalies such as congenital hearing loss, developmental delay. Clefts may occur as part of a syndrome/sequence or in association with other congenital anomalies (Watson et al., 2001: 87). Presence of syndromes in children with clefts affects communication development (Shprintzen & Bardach 1995: 38).		
D	Type of cleft	To describe types of cleft classified as: Cleft lip only, cleft lip and palate, cleft palate only and submucous cleft palate (Watson et al., 2001: 19). A further description of the type of cleft was noted for example if cleft palate only, whether hard and soft palate were involved or only soft palate. As the group under study was a heterogeneous it was important to document the types of cleft amongst these children. Cleft description is important when reporting a series of cases, as there is a need to compare one group with another and cleft type has implications for the management of the child (Watson et al., 2001: 23).		



**TABLE 4.4** Development and description of the interview schedule (continued)

	INTERVIEW SCHEDULE PHASE ONE			
SECTIONS	TYPE OF INFORMATION	OBJECTIVES AND QUESTIONS INCLUDED		
E (E1 & E2)	Surgical History	To describe characteristics of care provided to the children with CL/P. Information regarding the age of repair of lip, palate and if there were any secondary repairs was obtained. The timing of surgeries should be identified as the child's age at the time of repair has an impact on early speech-language development (Peterson-Falzone et al., 2010: 151). Questions regarding other surgeries that the child may have undergone were also asked for example, ears or heart or surgery for any other malformations.		
F (F1 to F3)	Feeding, Speech and Hearing	To describe parental perceptions of feeding and communication difficulties the child with CL/P exhibits and to address these concerns (Watson et al., 2001: 379). The other part of this section was the speech-language and Audiology services that the child was receiving and how frequently to describe the care provided to these children.		
G (G1 & G 2)	Pathway of care	To describe the clinical context of care provided to children with CL/P. Questions regarding who identified the cleft, when was the child first seen by the plastic surgeon, whether the child received services from other professionals were included. Children with CL/P require the services of an interdisciplinary team (ACPA, 2007: 5).		

# • Pre-testing of the interview schedule

The aim of pre-testing the interview schedule was to identify potential problems prior to finalising the contents of the interview schedule and the data collection procedure. Pre-testing was also carried out to improve the reliability and validity of the interview schedule (Neuman, 2000: 166).

# • Pre-test participants

- The pre-test participants had to be similar to the participants who would take part in Phase One. In order to detect potential problems that may be experienced when conducting the interview schedules on selected children with CL/P (De Vos et al., 2005: 209-211).
- Two children with CL/P who were older than six years were selected from the children with CL/P attending speech-language therapy services at ENT centre where the principal researcher works.
- Their parents participated as respondents of the interview schedule.
- In addition to the principal researcher, the three speech-language therapists and audiologists also participated, as they evaluated the tool.
- Materials for pre-testing the interview schedule
- The interview schedule was based on an in-depth literature review.
- The interview schedule was presented to the participating speech-language therapists and audiologists for comments and approval.
- The interview schedule developed was used as materials for the pre-test (refer to Appendix V). The hospital files and parents of the two children were the data sources in the pre-test.
- Procedure for pre-testing the interview schedule

- The principal researcher explained the purpose of the interview schedule to the parents of the two selected children. Voluntary consent to participate was obtained from the parents as respondents.
- The site for the interviews was the Speech Therapy unit at ENT hospital where families with children with CL/P access therapy services.
- The principal researcher conducted the interviews according to the interview schedule.

#### Results

The pre-test assisted the researcher in minimising the possibility that technical problems with the wording or layout may affect the data obtained by the questionnaire as survey instrument (Leedy & Ormrod, 2005: 188). The main results of the pre-test are listed below:

- Speech-language therapists and audiologists who acted as participants agreed that the *interview schedule was appropriate* as all the necessary information could be elicited to describe the characteristics of the children with CL/P using this tool.
- The *questions* were found to be clear and the respondents did not have any difficulty in answering the questions.
- *Parents* remained the primary source of information throughout the interview although hospital and medical records were available to verify information provided by them.
- It was determined that the average time to complete the interview schedule was approximately ten minutes.

Based on the results the data collection was carried out as described below.



# 4.7.4 Phase One data collection procedure

The data collection procedure for Phase One was as follows:

- During a brief meeting, the principal researcher presented the interview schedule to the participating speech-language therapists and audiologists and gave clear instructions on data collection procedures. All four participating speech-language therapists and audiologists (including the principal researcher) used the interview schedule to gather information in uniform manner from the respondents.
- Parents were contacted by telephone or letters to attend an interview at the regional hospital where they follow therapy. Interviews were planned during a routine appointment or at a time mutually convenient to the respondent (parent) and the therapist conducting the interview schedule. The regional hospital where the children attended routine follow-up appointments with the speech-language therapist and audiologist served as the venue.
- Medical records of each child were available to aid the respondents in recalling information for example the date of surgical repair of the cleft as a respondent may not recall past events when answering questions (Neuman, 2000: 255). The medical records were also useful in extracting information regarding the child's health.
- The principal researcher monitored that all information gathered by the speech-language therapists and audiologists was appropriately entered in the coded boxes provided in the interview schedule.

# 4.7.5 Phase One data recording and analysis

All data collected from the interview schedule were coded for statistical processing. The data were entered in Microsoft Excel and the statistician (Ministry of Health, Mauritius) used



statistical programme SPSS 10.0 for the data analysis. Descriptive statistics were applied for data analysis (Maxwell & Satake, 2006: 280; Morgan et al., 2006: 40). Discrete frequency counts were calculated for the variables (Morgan et al., 2006: 43). The data were displayed as bar charts and as pie charts. The numerical data such as ages were analysed for the mean while categorical data such as type of cleft and the binary data were analysed for percentages or proportions; (Morgan et al., 2006: 37). The data analysis is tabulated according to the objectives of Phase One of the study and illustrated in Table 4.5.



TABLE 4.5 Descriptive statistical analysis of Phase One (description of children with CL/P).

Data from Phase One	Purpose	Descriptive Statistical Procedure
A. Biographical Information	Compile a list of children with CL/P and provide a framework for future data entry into the electronic database	None
B. Family history	Description of the families  Languages spoken at home	Mean number of children in the families. Number of consanguineous marriages Frequency count, number of languages and percentages of children for variable languages (Maxwell & Satake, 2006:282)
C. Birth History	Characteristics of children, high risk factors for other anomalies and presence of syndromes	Percentages of children with non-syndromic CL/P, presence of syndromes or possibility of having syndromes (Morgan et al., 2006: 43).
D. Type of cleft	Classification in categories of the types of clefts	Frequency count of variable: cleft types depicted as bar chart according to sex of the child (Maxwell & Satake 2006: 282).
E. Surgical History	Description of surgical management	Age range; mean age and median age when cleft repair surgeries were performed (Leedy & Ormrod, 2005: 257).
F. Feeding, Speech and Hearing	Parental perceptions of child's difficulties Indication for speech-language and audiology services	Frequency count of children perceived by parents as having feeding, speech and hearing difficulties. (Leedy & Ormrod, 2005: 257).
G. Pathway of care	Description of identification and care provided	Frequency count and percentages of children managed by the various professionals involved in cleft care in Mauritius (Maxwell & Satake, 2006: 289).

The data of Phase One were analysed and interpreted to describe the characteristics of children with CL/P and pertinent information regarding family and languages spoken at home. The results were used to create a framework for compiling the Communication Assessment Protocol.



# 4.7.6 Phase One validity and reliability

The characteristics to be described concerned demographic information and care provided to the children with CL/P. The following strategies were applied to enhance validity and reliability, as they are central issues in all measurement (Neuman, 2000: 164).

Validity ensures that the instrument used for measurements in the study is measuring truth or close to truth and not subject to any errors of measurement (De Vos et al., 2005: 160; Maxwell & Satake, 2006: 127). The contents of the interview schedule (see Appendix V, Sections A-G) were prepared specifically according to the objectives of Phase One of the study. The process of establishing content validity is to see if the test items assess what the researcher wants them to (Maxwell & Satake, 2006: 128-129). Guidelines provided by the WHO (2001:70) and Craniofacial Anomalies Network (CRANE, 2000) regarding elements that need to be included when planning a database of children with CL/P and describing their characteristics, were followed. The core data elements for children included demographic information, maternal, and birth histories, and the types of clefts. Furthermore, the results obtained from the interview schedule were supported by the information available in the hospital records. Criterion related validity refers to the extent to which the results of a measuring instrument agree with those existing tests that are presumed to be valid (Maxwell & Satake, 2006: 130). The hospital records contributed to criterion validity. A detailed description of the study setting and systematic procedure for data collection were provided for any future researcher to judge the degree of transferability to another context and conduct a similar study. The largest sample possible was recruited (Maxwell & Satake, 2006: 30).so that the findings could be representative of Mauritius and possibly generalised to other contexts.



Reliability refers to the consistency with which the measuring instrument yields a certain result (Leedy & Ormrod, 2005: 29). In this phase the reliability of measurements was ensured by pretesting the interview schedule (see Section 4.7.3.2). The method of data triangulation as described by Leedy and Ormrod (2005: 99) was employed whereby medical records, parental interviews and observations of the child (type of cleft) were utilised when completing the interview schedule. The face-to-face interviews ensured a high rate of response that is important for the reliability of the research results. The researcher's generalisations may not be accurate if the number of non-respondents is high (Leedy & Ormrod, 2005: 209). In order to avoid bias the principal researcher utilized the other researchers to cross-check data that were gathered and often discussed the data collection procedures with them to ensure uniformity of data collection and recording. As depicted in Figure 4.1 this research was conducted in three sequential phases. The results of Phase One provided the necessary underpinnings for Phase Two.

#### 4.8 PHASE TWO

Phase Two was conducted to compile a Communication Assessment Protocol and to conduct assessments on selected children with CL/P in the Mauritian context.

# 4.8.1 Objectives of Phase Two

The objectives of Phase Two were to:

 Compile a Communication Assessment Protocol as a standard clinical tool for the assessment of children with CL/P in the age range 0-72 months, by speech-language therapists and audiologists working in the public health sector of Mauritius.



- Compile appropriate speech material (in locally spoken languages) for eliciting standard speech responses.
- Conduct assessments using the Communication Assessment Protocol on selected children with CL/P to evaluate the applicability of the tool.

The following Figure 4.8 illustrates the steps taken to achieve these objectives

# **PHASE TWO**

# **Obtained informed consent from participants:**

Parents of selected children with CL/P
Speech-language therapists & audiologists

# **Compiled the materials:**

Communication Assessment Protocol

Speech materials in locally spoken languages

Questionnaire: Perceptions of the speech-language therapists & audiologists regarding the Communication Assessment Protocol

# Conducted a pilot study

&

Trained the speech-language therapists & audiologists for data collection

Conducted communication assessments on selected children with CL/P

Analysed and interpreted data to describe characteristics of communication disorders in young children (0-72 months) with CL/P in Mauritius

FIGURE 4.8 Steps taken to compile and evaluate the applicability of the Communication

Assessment Protocol



# 4.8.2 Phase Two participants

The participants selected in Phase One of the study and the additional support staff also participated in Phase Two.

# 4.8.2.1. Children with cleft lip and/or palate

Eighty-eight children born with CL/P and described in Phase One (refer to section 4.7.2.1) also participated in Phase Two of the study.

#### 4.8.2.2. Speech-language therapists and audiologists

Three speech-language therapists and audiologists and the principal researcher described in Phase One (see Table 4.3) conducted the communication assessments of the selected children with CL/P and collected the data.

# 4.8.2.3. Additional support staff

The following support staff working at the Speech Therapy and Audiology unit, ENT centre participated during Phase Two:

- The *clerical officer* arranged the appointments for scheduled interviews and assessments of the children with CL/P.
- The *speech and hearing assistant* helped to make the audio and video recordings. The support of an additional staff member was required to carry out the recordings whilst the speech-language therapists and audiologists elicited speech from the children with CL/P.

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The speech and hearing assistant has a one-year in service training and five years of work experience to assist the speech-language therapist and audiologist.

# 4.8.3 Phase Two materials and apparatus

The materials used during Phase Two of this research are described in Table 4.6.

**TABLE 4.6** Materials compiled for use in Phase Two

Materials	Purpose
Communication assessment tracking form	To record the observations and the assessments conducted on the selected children with CL/P by the speech-language therapists and audiologists
Speech material	To elicit speech samples from children with CL/P in age range 36 to 72 months in the locally spoken languages
Questionnaire: Perceptions of the speech-language therapists and audiologists regarding the Communication Assessment Protocol	To determine the perceptions of speech-language therapists and audiologists regarding the Communication Assessment Protocol

The following Table 4.7 presents the Apparatus used during Phase Two.



**TABLE 4.7** Apparatus used during Phase Two

Apparatus	Specifications	Purpose
Electro-acoustic instruments for hearing evaluations	Screening Otoacoustic     Emissions Make:     Echocheck Otodynamics	To screen hearing amongst children younger than four months
These apparatus are available in the Speech- Therapy and Audiology Unit at ENT hospital and routinely used for hearing evaluations)	2. Brain Stem Evoked Response Audiometry. Make: Pilot Blankenfelde Evoselect 2 channels diagnostic testing	To diagnose hearing loss amongst children younger than 36 months
used for hearing evaluations)	3. Diagnostic Audiometer Make: GSI 61	To determine hearing thresholds amongst children 36-72 months
	4. Middle Ear Analyser  Make: Interacoustics AZ 26 (Probe 220 Hz).	To detect presence of fluid in the middle ear and acoustic reflexes
Video and audio recording equipment	Digital video Make: Sony Handycam Sony tripod stand VCT-R640 8 cms DVD + RW	To make high fidelity recordings of the elicited speech sample amongst children 36-72 months and carry out auditory perceptual speech analysis
		Recorded observations minimize interviewer bias allow for multiple judges and estimation of inter-rater reliability (Maxim, 1999: 300)
High fidelity recordings are ensured by digital recordings	Digital audio mini-disc Make Sony MD Walkman MZ-NH1 Recordable mini discs (80 minutes) External microphone tie pin ECM-C115 Headphones Sony stereo MDR-CD-280	To audio record the speech sample. An external microphone was used to ensure high fidelity recordings.  Headphones were used by the therapists when listening to the recorded speech for analysis



**TABLE 4.7** Apparatus used during Phase Two (continued)

Apparatus	Specifications	Purpose	
Training video Speech Assessments GOS.SP.ASS. '94 and '98	The Speech and language therapy Department at Great Ormond Street NHS Trust and DeMontford University Cleft Lip and Palate Association,	To provide the speech- language therapists ear- training on the phonetic characteristics associated with cleft lip and palate.	
Computer	Laptop, Make: Dell Pentium IV	To store the digital recordings and replay for speech analysis.	

# 4.8.3.1 Compilation of the Communication Assessment Protocol

The Communication Assessment Protocol was compiled as a clinical tool allowing speech-language therapists and audiologists to observe and enquire from the parents of the children with CL/P, and conduct series of communication assessments. The assessment tool was designed for children with CL/P in the age range 0-72 months. It is based on best practice (ACPA, 2000; Eurocran Speech Project, 2000; Kuehn & Moller, 2000) and recommendations in the literature as described in Chapter Two. The children were divided into two age groups as follows:

- Group 1: children with CL/P younger than 36 months and
- Group 2: children with CL/P in the age range of 36-72 months.

The CHRIB assessment protocol developed by the Department of Communication Pathology, University of Pretoria (Kritzinger & Louw, 2002) was the main reference source for the compilation of the Communication Assessment Protocol for Group 1 children. The protocol provides a description of a wide range of developmental areas related to early communication



development such as listening skills, pre-cursors for communication development and parental concerns regarding communication ability of their children (Kritzinger, 2000: 170).

For children in Group 2, the Great Ormond Street Hospital Assessment Protocol (GOS.SP.ASS.98) (Sell, Harding & Grunwell, 1999: 17-33) was selected as a main reference source because it provides a framework for speech assessment and analysis in a standardised way. It covers all features of speech associated with CL/P that are recommended for assessment (Henningsson et al: 2008). It includes evaluation of resonance, nasal emission, nasal turbulence, grimace, articulation characteristics and phonation together with systematic approach to an oral examination, the mirror test and description of the visual appearance of speech. It also facilitates systematic treatment planning (Sell et al., 1999). It was selected as an appropriate assessment tool for the age group 36 to 72 months because it uses simple perceptual methods to record and analyse speech.

A checklist for language acquisition (Shipley & McAfee, 2004: 233) and emergent reading skills (Snow, Burns, & Griffin, 1998) was also compiled. In the absence of local norms of language development, the speech-language therapists in Mauritius routinely use the checklist for language assessment from Shipley and McAfee (2004: 233). Therefore, it was selected as a checklist of language development in the Communication Assessment Protocol.

The content of the Communication Assessment protocol that was compiled from the literature review is depicted in Table 4.8.



**TABLE 4.8** Contents of the Communication Assessment Protocol

Areas of assessment	Age range	Aim	Compilation & test administration
A. Background Information	0-72 months	To describe characteristics of the child being assessed and the care provided to them by the Mauritius, public health sector	Described in section 4.7 Phase One and refer to Tale 4.4. Based on recommendations by WHO (2001) 'Global Registry and Database on Craniofacial Anomalies.
B. Feeding	younger than 36 months	To assess, advise parents regarding feeding & ensure adequate nutrition and weight gain, and if necessary refer to paediatricians and/or nutritionists	Based on Masarei et al. (2004). Two sub-sections are included:  Bi) Pre-cleft repair feeding and B ii) Post-palate surgical feeding assessments. SLTs and audiologists observe, assess feeding, and
			describe parental caregiver coping skills for feeding the child with CL/P.
C. Hearing	0-72 months	To monitor hearing, identify hearing pathology, and refer to ENT specialist	Based on Hugo, Louw, Kritzinger and Smit (2000) listening behaviour and established age appropriate hearing evaluations SLTs and audiologists note the history (high risk factors for congenital hearing loss), parental report of auditory behaviour, listening behaviour and evaluate hearing with electroacoustic instruments: TEOAE, BSERA, immittance measures, pure tone audiometry.
D. Orofacial Examination	0-72 months	To describe facial oral structures and function, report to plastic surgeon; refer for dental care and paediatric opinion.	Compiled from Kummer (2008: 351-375); Shprintzen and Bardach (1995: 211-215)  SLTs observe oral facial features and functions and check the appropriate items on the checklist format of the tracking form.



**TABLE 4.8** Contents of the Communication Assessment Protocol (continued)

Areas of assessment	Age range	Aim	Compilation & test administration
E(i) Communication Speech-language, assessment	0-36 months	To monitor communication identify difficulties/delay note consonant inventory, emergent reading skills and advise parents and provide therapy	Based on assessment at Facial Deformities Clinic at the University of Pretoria and the CHRIB  Early communication skills screening assessment, parental input of information and based on Thameside community heath care NHS trust consonant inventory. Speech-language therapists' and audiologists' observations
E(ii) Speech- language, articulation and voice, assessment	36-72 months	To monitor speech-language development, plan management of speech and voice	Based on GOS.SP.ASS.98. SLTs and audiologists will assess and record elicited speech samples.  A checklist for language acquisition (Shipley & McAfee, 2004: 233) and emergent reading skills (Snow, Burns & Griffin, 1998), is also included
F. General development	0-72 months	To monitor general development, note child's education history & make referrals.	Based on Shipley and McAfee (2004), parental reports and the speech-language therapists and audiologists' observations



- Design and layout of the Communication Assessment Protocol tracking form (refer to Appendix VI).
- A checklist questionnaire format was selected for the Communication Assessment Protocol in order to ensure uniform and accurate data recording by the speech-language therapists and audiologists. The observations and assessments of communication behaviours could be simply recorded by checking appropriate items on the list provided in the communication assessment tracking form. The checklist format facilitates data coding and analysis (Leedy & Ormrod, 2005: 185).
- The communication assessment tracking form consists of 15 pages and six sections: corresponding to the areas of assessment namely: background information, feeding, hearing, orofacial examination, communication, speech-language and general development. For each area of assessment, a different colour paper was used to improve clarity and easy identification of the various areas of assessment.
- The first 'summary' page is for recording background information regarding the child for example, demographic information, type of cleft and whether a syndrome is present. The summary page also contains areas of assessment, dates of assessment, name of the speech-language therapist and audiologist who carried out the assessment and the main recommendations.
- At the end of each section there is a box for the speech-language therapists and audiologists' recommendations and/or referrals for further management.



# 4.8.3.2 Compilation of the speech material for children with CL/P

The development of a standard procedure for assessing speech of children with CL/P is emphasized in current literature for reliable perceptual speech assessment and consistent reporting to allow for comparison of speech outcomes in the cleft population (ACPA, 2007: 3, Eurocran Speech Project 2000, Henningsson et al., 2008: 1-17; Lohmander-Agerskov & Olsson, 2004: 64, Sell et al., 2005: 103). In Mauritius, speech-language therapists use informal tests and procedures to assess speech production as no standardized tests have been developed for the local population. In order to overcome this gap, customised speech material to elicit speech samples from children in the age group 36 to 72 months was compiled, in accordance with international guidelines for developing suitable speech material for children with clefts within a country/language (Eurocran Speech Project, 2000).

Languages differ in relation to the distribution of speech sounds that are vulnerable versus relatively insensitive to the cleft palate condition (Hutters & Henningsson, 2004: 544). The two most commonly spoken languages, in Mauritius, are Creole and French (Phase One: Appendix V, item B.6). Speech articulation tests in French are available however a special articulation test for children with clefts was not found. A description of phonology of Mauritian Creole, contents of the speech material compiled and the procedures employed to prepare and pre-test the list of words and sentences in Creole follows.

#### Phonology of Creole



There are 26 phonemes in Creole namely 8 vowels, 14 consonants and 4 approximants (Baker, 1972: 40). In Creole the sibilant sound /ʃ/ is substituted by the phoneme /s/ (Pudaruth, 1972: 41). For example: /La bouche/ is pronounced /labousse/. The affricates /tʃ/ and /dʒ/, that are most vulnerable in cleft-type speech (Grunwell, 1993: 108), are absent in Creole. The linguapalatal rhotic sound /r/ of English and French is classified as an approximant in Creole (Baker, 1972: 40). The 14 consonants are shown in Table 4.9

**TABLE 4.9** Consonants in Creole

#### • Content of the speech material

A word list was compiled to elicit speech responses from the children with CL/P. The word list consists of the 14 consonants in Creole, tabulated above. Approximants and vowels are not included for assessment. The list includes 28 words in Creole to target syllable initial word initial (SIWI) and syllable final word final (SFWF) (Sell et al., 1999: 28). The French translation of the words is included in italics. These words are nouns that can easily be depicted by pictures (see Appendix VII) to facilitate the repetition task. In Creole the sounds /ʃ/ and /j/ are not used but in French these sounds are present therefore pictures representing these sounds were also included.

A list of sentences in Creole to target the 14 consonants is also included as repeating sentences is the recommended context for judging voice quality and resonance (Grunwell, 1993: 145;



Peterson-Falzone, Trost-Cardamone, Karnell & Hardin-Jones, 2006: 71; Peterson-Falzone et al., 2010: 279). Sentence repetition is a useful, economic and controlled way of collecting a data sample. Sentences chosen should be meaningful and relevant whilst containing maximal numbers of each target sound known to be vulnerable to the effects of cleft palate (Watson et al., 2001: 231-232). In clinical practice the speech-language therapists and audiologists in Mauritius use the French material from the 'Troubles de l'articulation', prepared by Equipe du Centre d'Orthophonie (n.d.). In accordance with guidelines by Eurocran, 2000 for preparing sentences to elicit speech samples a list of sentences was compiled from this resource material. Sentences in English have been standardized for this age group (36 to 72 months) of children with CL/P in GOS.SP.ASS.98. The English list of sentences was compiled along-with the Creole and French lists (refer to Appendix VII).

Procedure for preparing and pre-testing the compiled speech material

The following steps were taken to compile the speech material.

- Step 1: A preliminary list of speech material was prepared based on guidelines by Eurocran Speech Project (2000) and presented to the following experts in their respective field for their views and suggestions.
  - A linguist at the University of Mauritius
  - The director of a group of pre-primary schools
  - Speech-language therapists and audiologists working in the public health sector of Mauritius.



Based on their suggestions the final list was prepared.

A booklet with pictures of the words to be presented to and repeated by the children was compiled. Pictures facilitate the child's task of repetition and motivate children to repeat the words and sentences (Bernthal & Bankson, 1998: 250; Watson et al., 2001: 231). The pictures representing the words were selected and downloaded from the internet, printed in colour and compiled in a booklet (refer to Appendix VII).

A pilot study was conducted to pre-test the speech material prior to using it to elicit speech samples from the selected children with CL/P. Pre-testing the material helps to determine whether all the items are easy to understand, how long it takes to complete and identify possible problems (Leedy & Ormrod, 2005: 180). The aims, participants, materials, procedures and results of the pilot study are presented in Table 4.10.

The *speech material* was presented to the speech-language therapists and their opinion regarding acceptability of the material was sought. The consensus of the speech-language therapists and audiologists was that the speech material in Creole and French was age appropriate, culturally sensitive and acceptable for the main study. The English sentences were compiled from the standardised GOS.SP.ASS.1998 and were accepted as speech elicitation material by the speech-language therapists and audiologists.



**TABLE 4.10** Pilot study to develop the speech material

Aims	Participants	Materials	Procedure	Results
To determine whether children in age range 36-72 months can repeat the list of words and sentences.  To determine the amount of time needed for conducting the repetition to elicit speech samples	N=8 children  Sampling method: Consecutive and convenience sampling procedure  Selection criteria: -Gender: 4 male and 4 female -Age range: 36 to 72 months -Children with no speech-language problem -Children who speak Creole at home and could express in French (exposure to French at school)Siblings of children attending the speech-language services	The compiled speech material Creole and French.  The picture booklet  The English speech material in GOS.SP.ASS.98  APPARATUS  Digital audio mini-disc of make Sony MD Walkman MZ-NH1  Recordable mini discs (80 minutes)  External microphone tie pin ECM-C115	Verbal assent was obtained from the children to repeat the words  Speech sample was elicited by requesting the children to repeat the words then the sentences after the principal researcher.  Pictures representing the words were shown to the children whilst repeating the words as support material.  If the child spoke English only then speech sample in English was elicited  Digital audio recordings were made of each child's speech sample.	The speech material was age appropriate as more than 80 % of the children could repeat the compiled list of words and sentences in Creole and French (Carter et al., 2005: 394)  The children were cooperative and repeated all the words and sentences  It became clear that between each word repetition at least 5 seconds should be lapsed otherwise when listening to the recording speech analysis is difficult  The recording time ranged from 5 minutes to 7.30 minutes.



# 4.8.3.3 Questionnaire: Perceptions of the speech-language therapists and audiologists regarding the Communication Assessment Protocol

A questionnaire was designed to determine the perceptions of the speech-language therapists and audiologists regarding the Communication Assessment Protocol (refer to Table 4.8) based on Streicher (2005: 21-22). The questionnaire (refer to Appendix VIII) consisted of two sections, namely: Section I: Preliminary evaluation of the Communication Assessment Protocol.

Clinical applicability of the Communication Assessment Protocol.

Section I of the questionnaire was completed by the speech-language therapists and audiologists prior to conducting the Communication Assessment Protocol on the selected children with CL/P. Section II was completed during Phase Three *after* conducting the communication assessments. Section I, of the questionnaire, had 5 subsections and sought information regarding qualifications, work experience of participants, their opinion regarding the layout, content and design of the communication assessment tracking form. The self administered questionnaire design was preferred to an interview schedule to avoid interviewer bias (Babbie, 2001: 271; Neuman, 2000: 272). Closed-ended questions were included as the answers of different respondents are easier to compare and to provide response choices that can clarify question meaning for respondents (Neuman, 2000: 261). As the aim of the questionnaire was to determine the perceptions of the speech-language therapists and audiologists, open-ended questions were mixed with the closed-ended questions for the therapists to add and or explain their opinions. Results of the preliminary evaluation of the Communication Assessment Protocol by the speech-language therapists and audiologists prior to using the Communication Assessment Protocol are presented in Table 4.11.



TABLE 4.11 Perceptions of speech-language therapists and audiologists regarding the Communication Assessment Protocol

Section I: Perceptions of the speech-language therapists and audiologist regarding the Communication Assessment Protocol prior to using it. No Ouestion Responses of the speech-language therapists (SLTs) and audiologists: N= 3 (excluding the principal researcher) **P**1 P2 P3 Did the SLT and audiologist participate in Phase One of the study? Yes Yes No as she was 1. abroad -Did the SLTs and audiologists find the Communication Assessment Yes Yes Yes Protocol clear? - Would they like to include/exclude any of the areas? No No No - Whether training would be required? Yes in section E of No Yes in section E of If yes in which area? the protocol the protocol - Whether SLTs and audiologists could carry out auditory- perceptual Yes Yes Yes analysis of speech-voice according to the GOS.SP.ASS. 1998 and make the audio and video recordings planned. Yes Yes Yes - Whether the speech material is appropriate 4. - Opinion regarding length of the Communication Assessment Protocol May need more Unsure: may not Yes it is suitable for application in the hospital context than one session complete if child for the hospital to complete does not cooperate context 5. -An open question seeking their views. Comprehensive Very detailed Excellent protocol



As seen in Table 4.11 there was consensus among the speech-language therapists and audiologists regarding the feasibility of using the protocol clinically for conducting the communication assessments. The speech materials compiled in the locally spoken languages were also viewed to be appropriate. However, the three speech-language therapists and audiologists indicated a need for training in completing the communication, speech-language assessment for Group 2 children (refer to Appendix VI, Section E ii). The section is compiled from GOS.SP.ASS 1998 and requires perceptual speech and voice assessments. The local speech-language therapists required training to rate the voice resonance and note the cleft type speech characteristics during speech articulation in a uniform and standard manner. Therefore, training was provided to them prior to the data collection (refer to section 4.8.4.4).

# 4.8.4 Phase Two pilot study

The pilot study was conducted to carry out a smaller, preliminary version of the extensive study planned and to check the feasibility of the study. By rehearing the actual steps to be followed in the full-scale study, both small and big flaws are often revealed (Maxwell & Satake, 2006: 62).

# 4.8.4.1. Objectives of the pilot study

The objectives of the pilot study were to:

- Train the speech-language therapists and audiologists to administer the procedures for data collection purposes accurately and reliably.
- Evaluate the context (facilities) where the assessments would be conducted.
- Determine the feasibility of making the audio and video recordings.



# 4.8.4.2 Pilot study participants

The participants were the principal researcher and the three speech-language therapists and audiologists described in Table 4.3.

Eight children from the selected sample of 88 children with CL/P as participants were selected for the pilot study by a purposeful sampling method. These eight children were not included in the main study as communication assessments were conducted on them as part of the pilot study. The selected children and the speech-language therapists and audiologists conducting the assessment for the pilot study are described in Table 4.12.

TABLE 4.12 Description of children with CL/P selected for the pilot study.

Children	Gender	Date of	Group	Type of	Speech-language therapist &
with CL/P		Birth		Cleft	audiologist (N=4) conducting
N= 8					the assessment in her work
					context
1	F	01.03.05	1	СР	Participant 2 (SSRNH)
2	M	20.02.05	1	CLP	Participant 1
3	M	02.05.06	1	CL	Participant 4(JNH)
4	M	12.06.05	1	СР	Participant 3(Jeetoo hospital)
5	F	18.03.00	2	СР	Participant 4(JNH)
6	F	31.01.00	2	СР	Participant 1
7	M	29.10.00	2	SCP	Participant 2(SSRNH)
8	M	22.07.02	2	CLP	Participant 3(Jeetoo hospital)

Legend: CP-Cleft Palate only CL- Cleft lip only CLP- Cleft lip and Palate SCP-

Submucous Cleft Palate

SSRNH: Sir Seewoosagar Ramgoolam National Hospital, VH: Victoria Hospital,

JNH: Jawaharlal Nehru hospital

<sup>\*</sup> The pilot study was conducted between May and July 2006



# 4.8.4.3 Pilot study materials and apparatus

The materials and apparatus described in section 4.8.3 (see Tables 4.6 and 4.7) were used for the pilot study.

#### 4.8.4.4 Training of the speech-language therapists and audiologists

In this participatory action research, the speech-language therapists and audiologists were trained to conduct the assessments and complete the Communication Assessment Protocol in a uniform manner at the ENT hospital. This would in turn enhance the reliability and accuracy of the data collecting procedure. The speech-language therapists and audiologists studied the different items in the various areas of assessment that were to be observed and assessed. The principal researcher provided clear instructions regarding assessment procedures and checking of the observations in the Communication Assessment Protocol tracking form. The speech-language therapists and audiologists observed the principal researcher conducting the assessment according to the Communication Assessment Protocol. They were encouraged to ask the principal researcher for clarifications regarding the assessment procedure.

No additional training was required for conducting hearing evaluations, as using the apparatus in the audiology unit was a familiar task for the speech-language therapists and audiologists participating in the research. However, they were given explanations regarding age appropriate hearing evaluations for the purpose of this study.



The audio-video recording procedure was demonstrated to the speech-language therapists and audiologists to familiarise them with the recording equipment. The recording apparatus (refer Table 4.7) is very user friendly, formal training in its use was not indicated.

In preparation for the research, the principal researcher had previously received training in the use of GOS.SP.ASS.98 at Great Ormond Street Hospital. The administration and speech analysis procedures were shared with the speech-language therapists and audiologists participating in this study. The training procedures were as follows:

- The objective of training was to familiarize the participants with the description and rating of resonance and cleft type speech characteristics for children with CL/P according to the GOS.SP.ASS 1998 (Sell et al., 1999). Moreover, training the speech-language therapists and audiologists would ensure uniform data collection, and improve listener judgement for speech analysis.

- The *apparatus* used was the training video Speech Assessments GOS.SP.ASS 1994 and 1999. The 35 minutes training video focuses on the administration and scoring of the speech elicited responses. The video provides a description of resonance characteristics (hypernasality, hyponasality and mixed nasality) and explains the evaluation procedure using a rating scale. Other cleft speech characteristics such as nasal emissions, nasal turbulence and identifying their presence are illustrated in the training video as well. The video also covers speech patterns of individuals with cleft palate and provides an overview of phonetic transcriptions with appropriate diacritics of these error patterns (dentalization, lateralization, palatization, glottal speech). Perceptual differences between nasal resonance, nasal emissions and between cleft type speech errors and developmental errors are demonstrated. The training video concludes with



practice sentences as an opportunity to practice identifying, rating and transcribing cleft speech characteristics.

- The speech-language therapists and audiologists viewed the GOS.SP.ASS. '98 training video twice (a week apart for each viewing). They watched the video and discussed the procedures for applying the GOS.SP.ASS protocol in the Mauritian context using the speech material compiled in Creole. The video was available for individual viewing and practice in listening to cleft speech patterns. The viewing sessions were followed by discussions on speech assessments. Furthermore, the principal investigator, who, as described earlier, had training in administration and scoring of speech in accordance with GOS.SP.ASS, demonstrated its application to the participating speech-language therapists and audiologists.
- The original GOS.SP.ASS 1998 was modified for the purposes of this study. The participants did not transcribe the speech using phonetic and diacritic symbols for cleft type speech as described in the video as they had limited training in transcribing speech phonetically. They used letters representing the consonant sounds and descriptions of the speech sound production. The GOS.SP.ASS '98 rating conventions were modified and reduced to binary judgments of presence or absence of speech errors. The speech elicitation material in this study was in 'Creole' and 'French' (described in section 4.8.3.2), and the speech-language therapists and audiologists in Mauritius are inexperienced in transcribing spoken Creole/French. In the future, training in transcribing speech and phonetic diacritics to record cleft type speech characteristics in the local language should be included to conform with best practice recommendations (Henningsson et al., 2008:7-8; Peterson-Falzone et al., 2010: 274; Sell, 2005: 106).
- Each child with CL/P in the sample was requested to repeat the words and sentences contained in the speech assessment material while digital audio and video recordings of their speech



production in Creole and French were made simultaneously. If the child did not respond, a further attempt was made to elicit speech production by showing the pictures depicting the words and encourage repetition of the speech material. The digital video and audio systems were high fidelity recordings that are amenable to computer storage, and playback of audio and video information (Sell, 2005). The participating speech-language therapists, assessed speech based on perceptual analysis of the audio and video recording of the speech samples (repetition of words, sentences and global impression of speech). Recorded observations minimize assessor bias and allow for multiple speech analyses and estimation of inter-assessor reliability. The principal researcher ensured that the stored data were available for further analysis (inter-assessor reliability checks) and as archives to aid future research.

#### 4.8.4.5 Pilot study data collection procedure

Telephonic appointments were scheduled to conduct the assessments on the eight children selected as participants for the pilot study at the ENT centre: Speech Therapy and Audiology Unit. The test administration procedure was explained to the parents by the principal researcher. Parental consent to make audio-video recordings for children from Group 2 (36-72 months) was obtained. Whenever appropriate for the child, his or her assent was obtained prior to making the recordings.

The principal researcher herself carried out the first two assessments so that the speech-language therapists and audiologists could observe the data collection procedure. Written instructions regarding completing the Communication Assessment Protocol tracking form were given to each



of the speech-language therapists and audiologists. Each speech-language therapist and audiologist conducted the communication assessment as per the protocol on two children. The assessment included the interview with the parents of the child, observations of the child, eliciting speech responses, conducting hearing evaluations and recording the data on the Communication Assessment Protocol tracking form by checking the appropriate choice in the box provided. The speech-language therapists and audiologists were encouraged to ask the principal researcher for clarifications and help in recording the data while carrying out the assessment during the pilot study.

The principal researcher made the digital audio and video recordings for children from Group 2 whilst the participant speech-language therapist and audiologist requested the children to repeat the speech material. The principal researcher also noted the time taken to complete the communication assessment.

# 4.8.4.6 Pilot study results

The results are presented in accordance with the objectives of the pilot study:

- The sequence of the tracking form was feeding, hearing, orofacial examination, communication, speech-language and finally general development. During the pilot study the following sequence for assessment was found to be more convenient and practical:

feeding, orofacial examination, general developmental history, followed by communication, speech-language assessment and lastly the hearing evaluations. The revised sequence was agreed upon by the speech-language therapists and audiologists for the data collection procedure in the main study.



- The hearing evaluation apparatus (Table 4.7) was easy to use as the speech-language therapists and audiologists were experienced in differential diagnostic hearing tests using the same apparatus. The apparatus are used regularly and calibrated annually. Thus the speech-language therapists and audiologists were able to collect accurate, valid and reliable data.
- It was found that the speech-language therapists and audiologists could not simultaneously prompt the children (in age Group 2) to repeat the words and make audio and video recordings. Therefore, it was decided that the principal researcher would record whilst the speech-language therapist and audiologist encouraged the child to repeat the speech material. The principal researcher was responsible for transferring the audio and video recordings to the computer for storage and back-up of the digital recordings.
- The speech-language therapists and audiologists felt the need to watch the training video again to clarify the completion of speech assessments (refer to Appendix VI, Items E26-E31). However, they did not feel competent to transcribe the cleft type speech phonemes with the diacritic symbols as proposed in the training video. More detailed transcription provides greater information, but has limited reliability (Bernthal & Bankson, 1998: 239; Gooch, Hardin-Jones, Chapman, Trost-Cardamone, Sussman, 2001; Kent, Weismer, Kent, Vorperian & Duffy, 1999: 144). Therefore, consensus was reached that the following symbols would be used; + if the phoneme was articulated correctly and if any type of error in the phoneme production was perceived.
- The speech therapy and audiology unit at the ENT centre of the Victoria Regional Hospital was deemed to be a suitable site for carrying out the assessment as it was the most centrally located hospital on the island with easy access for the participants. The test environment was quiet; with heavy carpets and curtains and a blue background for the video recording (recommended by



Eurocran, 2000) already in place. Hearing evaluation apparatus was available with the infrastructure of sound treated rooms (a facility not available at each of the regional hospitals). Therefore it was decided that all the assessments for data collection would be conducted at the ENT Centre.

- The average time taken for completing the assessment varied. The assessment of children in Group 1 took 40 minutes for those in Group 2 approximately 60 minutes were required as speech samples were also collected. This was considered to be a reasonable time for completing communication assessment in a clinical context (Williams, 2002: 211) and therefore no modification of the protocol was deemed necessary. As the speech-language therapists and audiologists became more experienced in applying the protocol, the time to complete the assessments decreased.
- The 15 pages of the Communication Assessment Protocol tracking form were printed on white paper. To facilitate the assessment process and improve the appearance of the form, a different colour paper for each of the six areas of assessment was chosen. Please refer to the Communication Assessment Protocol in Appendix VI.

## 4.8.5 Phase Two data collection procedure

After completion of the pilot study and the training of the participating speech-language therapists and audiologists, the data collection process for the main study was initiated. The 80 children selected as participants for the main study were divided into two groups based on age.

Group 1 consisted of 24 children younger than 36 months and Group 2 consisted of 56 children between 36 and 72 months (Table 4.2). Eight children from the eighty-eight participants in



Phase One of the study had been selected for the pilot study therefore these children were excluded from the main study.

The clerk scheduled the assessment appointments for the 80 children acting as participants. The appointment schedule for the communication assessment was on an individual basis at a convenient day and time for the speech-language therapists and audiologists and the parents who were expected to bring their children to the hospital. Two children with CL/P were assessed per day and appointments were made over four days of the week. The appointments were made by telephone at the beginning of each week. In cases where the telephone number was, not available appointment letters were sent out suggesting a time when the parent could attend or they could call to change the appointment. The data collection for Phase Two of the study was conducted over a five-month period starting in August 2006.

The purpose of the assessment and process were communicated to the parents. They were requested to sign a consent form before proceeding with the assessment. The hospital clerical officer signed as a witness. Child assent, if possible, was obtained before proceeding with the Communication Assessment Protocol. The speech-language therapist and audiologist who would conduct the assessment made the child comfortable and established rapport prior to conducting the assessment. Firstly, the speech-language therapist and audiologist conducting the assessment noted the essential background information and relevant details from the questionnaire completed during Phase One of the study and then proceeded with the communication assessment.



The sequence of areas of assessment for children in Group 1 followed was feeding, orofacial examination, general development, communication, speech-language and finally hearing. Feeding assessment was conducted only for children younger than 36 months. Hearing evaluations were carried out at the end, as the children were more comfortable and responsive towards the end rather than beginning of the assessment. All the data pertaining to the various areas of assessment were summarised and reported on the first page of the tracking form (Appendix VI).

Assessments of children in Group 2 were conducted in the following sequence: hearing evaluation, orofacial examination, general development, communication speech and language assessment and finally summary of the results. Speech samples were obtained from the children in Group 2 and simultaneous audio and video recordings were made.

The procedure for obtaining the speech sample from children in Group 2 (Appendix VI: Items E26 to E33) was as follows:

- The conversation with the child was recorded and each child was requested to describe a picture (a seaside scene).
- In addition to the elicited speech responses, the Eurocran Speech Project (2000) recommends rote speech and a small amount of spontaneous speech as this makes it possible to detect any major differences between a child's speech in conversation and in controlled speech. Therefore, the children with CL/P were requested to count either 1-5 or 1-10. Counting is a means of eliciting connected speech from very young children (Kummer, 2008: 327).

- The speech-language therapists and audiologists obtained speech samples for recording and analysis by requesting each child to repeat the words and sentences using the speech material prepared in Creole and French. If the child did not respond, a further attempt was made to show the pictures depicting the words to elicit speech.
- The speech-language therapists and audiologists conducting the assessments had checked the appropriate coded items. In each of the sections, B through F of the compiled Communication Assessment Protocol (refer to Appendix VI) boxes are provided for checking the recommendations and or referrals based on the assessments carried out.

After completing the communication assessments, the speech-language therapists and audiologists explained the reasons for making referrals or recommendations to the parents. Children who required regular speech-language therapy sessions were given subsequent follow-up appointments. The speech-language therapists and audiologists checked the tracking form to make sure that all the areas of assessments had been completed. They also noted the time taken to complete the assessment. The principal researcher made a back-up copy of each digital video and audio-recorded speech sample to ensure storage of data for further analysis (inter-rater reliability checks) and as archives for future research.

Perceptual speech analysis of the recorded speech sample of the children from Group 2 was carried out by the speech-language therapist and audiologist who conducted the assessment based on the video and audio recordings immediately after completing the communication assessment. The principal researcher checked the tracking forms for completeness before handing over the forms to the medical statistician in the ministry of health for data entry in Microsoft Excel 2000 and statistical analysis with the SAS programme.



## 4.8.6 Phase Two data analysis

Descriptive statistics were used for the data analysis (De Vos et al., 2005: 225). The categorical data (cleft type) and the binary data were analysed for percentage or proportions; (Morgan, 2006: 37). The data were presented in a tabular or bar diagram for the discrete frequency counts of the selected variables. Cumulative frequency graphs were used to represent the number of children with CL/P referred for further management to specialists. Qualitative analysis of textual data, for example parental concerns regarding communication, was carried out and described. For the purpose of this study the following items were analyzed as shown in Table 4.13.

**TABLE 4.13 Data analysis of Phase Two** 

Items from data collected (refer to Appendix VI)	Purpose	Descriptive Statistical Procedure
A. Summary sheet A5 Type of cleft and A6 Presence or absence of syndrome/sequence	The demographic information and essential background information concerning the child at a glance the dates of assessment, the professional conducting the assessments and the recommendations.	Frequency counts of children displaying each of these characteristics
B. Feeding assessment Bi) Pre-cleft repair feeding assessment Items B12 to B15 current feeding method. B36 identify risk for poor weight gain	Children younger than 36 months: N= 24  To describe the feeding methods and identify whether the child with CL/P is at risk for poor weight gain.	Description of feeding method Frequency count of children referred to other professionals as at risk of poor weight gain according to type of cleft (Maxwell & Satake, 2006:282).
B ii) Post-surgical feeding assessment Item B 45, B 46, B47 B52	Identify the child with oronasal fistula, nasal regurgitation and feeding difficulties and risk for poor weight gain post-operatively.	Frequency count of children (Maxwell & Satake, 2006: 282).

C. Hearing evaluation	N= 80	Frequency count
Item C4	Past history of ear surgery	Description of the risk
Item C7	To determine risk factors for hearing	factors
Item C8	loss.	Frequency count of the
Item C17	Listening skills of the children	children identified with
Items C18, C19	To determine the type and degree of	hearing loss. A cross
110.115 616, 615	H.L.	tabulation with listening
	Identify children with hearing loss	skills and hearing loss.
	requiring referral to ENT specialist	(Maxwell & Satake, 2006:
	and or recommendations for hearing	282).
	aids.	
D. Orofacial examination	N= 80. Identify the contributing	Frequency counts and
Items D20, D21, D22 and	factors to speech production errors.	number of referrals for
D23.	Number of children referred for	opinion of other
	further assessment to dentist, ENT	professionals (Maxwell &
	specialists and/or other referrals.	Satake, 2006:282).
E. Communication, speech	The sample was divided into to age	None
and language assessment	groups	Description of
E i) Children younger than	N=24	characteristics of the
36 months	Identify child with speech-language	children with CL/P
	difficulties and or delay.	Frequency count of
Items E9, E12,		children requiring in-depth
, ,		assessments and parental
		guidance.
E ii) Children 36- 72	N= 56	Frequency count of
months	To identify children having speech-	children requiring regular
Items E35	language difficulties	speech-language therapy
		(Maxwell & Satake,
		2006:282).
Item 34	Identifiable causes of communication,	Frequency count according
	speech and language difficulties	to type cleft (Maxwell &
		Satake, 2006:282).
Items E26, E27, E28,	According to GOS.SP.ASS '98	Description and discussion
	description of type of resonance	of speech and voice
E31, E32, E33	problems and cleft speech	production based on
	characteristics identified	perceptual analysis of
		audio and video recordings
		of the speech samples.
		(Sell, 1999)
F. General Development	N= 80.	Frequency count of
Items F9	To note number of children attending	children attending school.
740	school	Number of children
F10	To note any parental concerns	referred for in depth
	regarding general development of the	assessments to other
Item F12.	child. To determine the need for	professionals (Leedy &
	other team members' assessment.	Ormrod, 2005: 257).



## 4.8.6 Phase Two validity, reliability and trustworthiness

In Phase Two a mixed methods approach (both quantitative and qualitative) to data collection was used. In quantitative research the quality criteria are validity and reliability whereas in qualitative research the quality criteria is trustworthiness (De Vos et al., 2005: 351). Therefore validity, reliability and trustworthiness are discussed.

**Validity** of the compiled Communication Assessment Instrument was ensured by the following strategies:

- An in-depth literature review was carried out to identify important areas of communication for young children with CL/P, 0-72 months. A measurement instrument has high content validity if its items reflect the various parts of the content domain and the particular behaviours and skills that are central to the domain (Leedy & Ormrod, 2005: 92). Moreover, the Communication Assessment Protocol was compiled from existing protocols that are used in established centres of speech-language therapy and audiology such as University of Pretoria (South Africa) and the Great Ormond Street Children's Hospital (UK) for communication assessment of children with CL/P.
- Speech assessment material for children in age group 36-72 months in the Mauritian Creole language was included in the instrument for measurement of speech sample. Eurocran (2000) guidelines on preparation of speech material for children with CL/P were followed. On the basis of the judgment of the experts (refer section 4.8.3.2) and opinions of the participants namely the speech-language therapists and audiologists who carried out the assessments, content validity was ensured (De Vos et al., 2005: 161; Leedy & Ormrod, 2005: 93).

- External validity was ensured by providing detailed descriptions of the clinical context of management of children with CL/P within the public health sector and the setting where the Communication Assessment Protocol was administered (Morgan et al., 2006: 50).

**Reliability**: The principal researcher and three other speech-language therapists and audiologists were the observers and data gatherers. The following steps were taken to ensure accuracy and consistency of measurements (De Vos et al., 2005: 162; Leedy & Ormrod, 2005: 29).

- A pilot study was conducted prior to proceeding with the main study to improve the reliability of the measure (Neuman, 2000: 166).
- The data gathered by the speech-language therapists and audiologists was in a uniform manner using the same Communication Assessment Protocol. Administration of the test in a consistent way enhances the reliability of the measuring instrument (Leedy & Ormrod, 2005: 93).
- Training of the speech-language therapists and audiologists in completion of the form, particularly the auditory-perception assessment of the cleft type speech characteristics, enhanced uniform assessment procedures and replication.
- Perceptual analysis of the audio and video recording of the speech samples were carried out by the speech-language therapists and audiologists (Sell, 2005: 103-121). Recorded observations minimize interviewer bias; allow for multiple judges and estimation of inter-observer reliability (Sell, 2005: 107). In order to establish inter-observer reliability, the four speech-language therapists independently listened to the audio and video digital recordings of a random selection of eight recordings. The percentage agreement among the four speech-language therapists was calculated for hypernasality, nasal emission and cleft type speech characteristics of the recorded speech samples. The 'trustworthiness' of conducting assessments using the Communication Assessment Protocol is depicted in the following Table 4.14.



**TABLE 4.14 Trustworthiness of Phase Two** 

Tweetyvouthings	Ctuatagy
Trustworthiness Cradibility	Strategy The principal researcher has been involved in the care of children
Credibility  Within the parameters of the setting, population and theoretical framework the research will be valid (De Vos et al., 2005: 346)	The principal researcher has been involved in the care of children with CL/P with the plastic surgeon at Victoria Regional Hospital since 15 years. This prolonged involvement ensured trust between the researcher and the participants. An in-depth description of the setting and participants allows the reader to judge the credibility of this phase of the study.  The Communication Assessment Protocol was based on a thorough literature review and consultations with experts; Prof. B. Louw at University of Pretoria and Dr. D. Sell, Lead Speech-language therapist at the Great Ormond Street Hospital, London. The compilation of the Communication Assessment Protocol was based on areas of assessments that had sound theoretical underpinnings and standardized and credible components were incorporated for example the GOS.SP.ASS '98 for perceptual speech assessments. Maxwell & Satake (2006: 129) suggest seeking expert opinion to establish content validity of a measuring instrument.
	Member checking, consensus of the speech-language therapists and audiologists during data analysis and inferring the results further ensured the credibility (Denzin & Lincoln, 2000: 96)
Transferability  Designing a study in which multiple cases, multiple informants are used can strengthen external validity (De Vos et al., 2005: 346)	Detailed description of the children as participants (including demographic information) and systematic description of the research methodology such that any investigator could judge the degree of transferability to set up a communication assessment protocol in another context. The researcher involved other speech-language therapists and audiologists, in the use of the Communication Assessment Protocol throughout the research project to encourage their active participation in the development of the protocol so that they would be more willing to use the protocol in their clinical practice.
Dependability  Reliability of the study (De Vos et al., 2005: 346)	Feedback (peer opinion) from the speech-language therapists and audiologists regarding the Communication Assessment Protocol, through questionnaire survey and discussions were strategies incorporated in Phase Two to ensure reliability and dependability of the Communication Assessment Protocol.
Conformability  Objectivity of the study (De Vos et al., 2005: 347)	The four speech-language therapists and audiologists; working in the public health sector of Mauritius, conducted administered the Communication Assessment Protocol using the same form and methodology. Inter-observer agreement percentage helped remove researcher bias and enabled data collection procedure that was objective to some extent. A combination of digital audio and video recordings was made for confirming the speech assessment procedures and interpretations by the researcher.



#### 4.9 PHASE THREE

Phase Three was conducted at the end of the study and adopted a mixed sequential methodology approach for data collection and analysis. Both the quantitative and qualitative data was analyzed and interpreted.

#### 4.9.1 Objective of Phase Three

Phase Three was conducted to determine the perceptions of the speech-language therapists and audiologists regarding the acceptability of the Communication assessment Protocol. In Figure 4.9 the steps taken to achieve this objective are illustrated.

## **PHASE THREE**

Speech-language therapists and audiologists completed a questionnaire regarding the acceptability of the Communication Assessment Protocol

A focus group discussion was held as an adjunct qualitative method to the questionnaire to determine the acceptability of the Communication Assessment Protocol

Analysed and interpreted the data to evaluate the Communication
Assessment Protocol's acceptability by the speech-language
therapists and audiologists for routine clinical use.

FIGURE 4.9 Steps taken to evaluate the acceptability of the Communication Assessment Protocol



# 4.9.2 Phase Three participants

The participants of Phase Three are described in this section.

#### 4.9.2.1 Speech-language therapists and audiologists

The speech-language therapists and audiologists who took part in Phases One and Two also participated in Phase Three. They were chosen for determining the clinical acceptability of the protocol because they had gathered the data in the first two phases of the study, were knowledgeable and experienced with regards to the topic of discussion and could provide rich information (Patton, 1990: 169; Welman et al., 2005: 202).

#### 4.9.2.2 Additional support staff

The speech and hearing assistant described in section 4.8.2.3 participated in Phase Three to record the focus group session. She previously contributed to Phase Two by carrying out the audio and video recordings of the children's speech while the principal researcher conducted the assessments. She was selected for Phase Three to share her experiences of the recordings.

A facilitator for the focus group discussion was selected, to limit the principal researcher's bias (Creswell, 2003: 189), on the basis of following criteria:

- *Employment context*: The facilitator was required to be employed by the public health sector, so that he/she is familiar with the clinical service delivery system of the health sector in Mauritius.
- *Experience*: The facilitator should have experience in holding focus group sessions and adequate knowledge of the topic (De Vos et al., 2005: 307; Krueger, 2007). For this study the facilitator was required to be aware of the methodology employed in developing the Communication Assessment Protocol to facilitate the discussions.

- *Language*: The preferred language for the focus group session was English as the speech-language therapists and audiologists communicate amongst themselves in English. It was therefore necessary that the facilitator is fluent in English to conduct the focus group interview.

- *Gender*: The participants must feel comfortable with the facilitator. As the participants of the focus group discussion were female a facilitator of the same gender was deemed to be appropriate (De Vos et al., 2005: 307).

A female medical practitioner, employed as a training officer at the Mauritius Institute of Health since 1992, met all the above criteria and agreed to act as the facilitator.

## **4.9.3** Phase Three materials and apparatus

## 4.9.3.1 Data collection instrument: Questionnaire

A questionnaire was developed to determine the perceptions of the speech-language therapists and audiologists regarding the Communication Assessment Protocol based on that of Streicher (2005: 38). The questionnaire (section 4.8.3.3 and Appendix VIII) consisted of two sections; section I for the preliminary evaluation of the Communication Assessment Protocol and section II for clinical applicability and acceptability. Section I was administered during Phase Two, prior to the conduction of the Communication Assessment Protocol and was described with results in section 4.8.3.3.

Section II of the questionnaire was completed by the participants *after* conducting the communication assessments on children with CL/P (section 4.8). The aim was to determine perceptions of the participants regarding the clinical applicability and acceptability of the Communication Assessment Protocol. Both closed-ended and open-ended questions were used



in the self-administered questionnaire in a check-list format to determine the perceptions of the speech-language therapists and audiologists (refer to Appendix VIII, Section II). Closed questions were asked to help the speech-language therapists and audiologists answer the questions within the same framework and response choices clarified the responses (De Vos et al., 2005: 175). Closed questions offer an easier analysis and statistical processing of the data (De Vos et al., 2005: 175). However, to determine what the speech-language therapists and audiologists' perceptions were, open-ended questions were used to encourage the participants to express their opinions and views freely (Babbie, 2001: 240; Neuman, 2000: 261).

TABLE 4.15 Section II: Contents of questionnaire to determine the clinical applicability of the Communication Assessment Protocol

CECTION II	C
SECTION II	Contents of the questionnaire
Question and sub-	
questions	
4000000	
1	Experience in applying the protocol based on the number of children
	with CL/P that the therapist as participant researcher assessed using the
	communication assessment protocol.
2	Experiences regarding administration of the Communication
	Assessment Protocol
3	Perceptions regarding the rating scale of resonance and description of
	the cleft type speech characteristics when conducting the
	communication assessments on children with CL/P in group 2 (36-72
	months).
4	Experiences regarding compliance of children with CL/P during the
	assessment.
5	Opinion regarding intervention goals and referrals based on the
Č	Communication Assessment Protocol.
6	Experiences regarding the practical application of the Communication
	Assessment Protocol in the hospital context.
7	Open-ended question for comments and recommendations of the
	speech-language therapists and audiologists



## 4.9.3.2 Focus group topic guide

A focus group discussion was held after administration of the questionnaire to collect additional data (Stewart & Shamdasani, 1990: 15). The facilitator was provided with the topic guide and the Communication Assessment Protocol so that she understood the intent of the questions (Stewart & Shamdasani, 1990: 61).

Three main topics to conduct an in-depth exploration of the views of the participants regarding the acceptability of the Communication Assessment Protocol were identified. A topic guide was prepared to ensure that the focus is the research problem and most of the questions related to it are discussed during the focus group session (Bloor et al., 2001: 43; Leedy & Ormrod, 2005: 147; Stewart & Shamdasani, 1990: 60). The discussion started with general topics and gradually dealt with more specific topics pertaining to the acceptability of the Communication Assessment Protocol.

Topic One: An overview

The aim of introducing topic one was to obtain participants' holistic views of the acceptability of the Communication Assessment Protocol. The suggested trigger question in the topic guide was:

What are your opinions and views regarding the Communication Assessment Protocol?

Topic Two: Specific details: Contents of the protocol and the practicalities of conducting the assessments

The aim of topic two was to obtain the participants' views regarding assessment, training and practicalities of conducting the assessment.

The suggested trigger questions were:



- What did you think about the training provided in administration of the communication assessment protocol?
- Would you like to share your experiences?
- Your comments regarding the materials provided: for example the speech elicitation materials, the pictures to elicit speech responses from the children.
- Would you like to comment on the apparatus that was used for hearing evaluations and for making the audio and video recordings?
- Please comment on your experiences when analyzing the speech of children in group 2 (36-72 months). What did you think about the recordings during play back for analysis?

Topic Three: Implementation of the Communication Assessment Protocol

The aim of topic three was to gather views regarding clinical implementation of the protocol.

The suggested trigger questions were:

- What do you think about the clinical applicability of the communication assessment protocol? Could you base your intervention goals on the Communication Assessment Protocol?
- Could you identify the possible etiological factors and make referrals on the basis of the assessments conducted? Do you think that you will use the Communication Assessment Protocol in the future?

The sequence of the topics and trigger questions were planned to focus the discussions in such a way that the data analysis and interpretations would enable the principal researcher to conclude whether the Communication Assessment Protocol was acceptable for clinical use to the speech-language therapists and audiologists.



## **4.9.3.3** *Apparatus*

The video and audio recording apparatus (described in Table 4.7) was used to record the focus group discussion. Three DVD-RW discs (30 minutes each) were used for video recording. One recordable audio mini disc (80 minutes) and an external multidirectional microphone were the accessories that were used for high fidelity recordings.

## 4.9.4 Phase Three data collection procedure

The data collection procedures of Phase Three included a self administered questionnaire that was completed by the speech-language therapists and audiologists. The last phase of the participatory action research was their participation in a focus group discussion.

#### 4.9.4.1 Self-administered questionnaire

The principal researcher individually contacted each speech-language therapist and audiologist and handed over section II of the questionnaire for completion. Participants were requested to complete the questionnaire one week before the scheduled date of the focus group interview so that they could express their unbiased opinion individually. The principal researcher collected the completed questionnaires from the three speech-language therapists and audiologists and analyzed the responses.

The topics selected for the focus group discussion were based on the results of the questionnaires.



## 4.9.4.2 Focus group discussion

The *objectives* of the focus group discussion were:

- To supplement and enrich the interpretation of responses from the speech-language therapists and audiologists (Bloor et al., 2001: 9).
- To generate collective views of the participants. Babbie (2001: 294) suggests that group dynamics bring out aspects of the topic that the researcher may not have anticipated.

The small number of participants meant that each participant was able to express her views fully. The potential risk of a small group is cancellation if even one or two participants fail to turn up (Bloor et al., 2001: 26-27). To ensure attendance of all the participants the venue, date and time of the focus group was planned in consultation with the participants.

The venue selected was the Mauritius Institute of Health (MIH) as the required facilities; a comfortable quiet room free from any interruptions, table and chairs to accommodate six persons are provided. Also the MIH is conveniently situated close to the Speech Therapy and Audiology unit at the north region hospital the SSRNH. In addition the facilitator works at the MIH. The participants agreed that MIH was a suitable and accessible venue. Transport facilities were offered to them to reach the venue.

The duration of the focus group discussion was 90 minutes as recommended in the literature for a focus group discussion (De Vos et al., 2005: 309; Leedy & Ormrod, 2005: 146). The principal researcher confirmed the focus group interview one week before with each of the participants and made follow-up phone call to every participant the day before the scheduled date (De Vos et al., 2005: 305).



The facilitator and the principal researcher welcomed the participants and refreshments were served. Rapport was quickly established (Leedy & Ormrod, 2005: 147) as the speech-language therapists knew each other and shared similar professional experiences.

The facilitator introduced herself and instructed the participants of the ground rules of the focus group session. The beginning of a group session sets the tone and agenda for all that follows (Stewart & Shamdasani, 1990: 92). The language in which the participants usually communicate amongst themselves is English, therefore the group agreed to converse in English. Consent was obtained from the participants to video and audio record the proceedings. The non-verbal cues are invaluable in the data analysis of focus group interview (Stewart & Shamdasani, 1990: 16). When recordings are made it is customary to acknowledge its presence while assuring group members that the recording will remain confidential and that its circulation will be limited (Stewart & Shamdasani, 1990: 92). The audio recording was made to facilitate writing the transcript for analysis (Bloor et al., 2001: 41-42). The speech-language therapists and audiologists gave their consent to the video recordings (refer to video recording of focus group discussion attached to back cover). The facilitator opened the discussion for the themes prepared and encouraged each participant to express their views. The speech and hearing assistant video recorded the focus group discussion. The assistant helped with the video and audio recordings of the children's speech recordings during Phase Two; therefore, she participated in the discussion to express her experiences as an assistant. During the session, the principal researcher made descriptive notes of the focus group discussion and was a silent observer participant so as to avoid any form of bias (Creswell, 2003: 189).



The facilitator gave short summaries of each topic discussed and member checks were made to clarify the perceptions expressed by the participants by asking the members if they agreed, disagreed or would like to bring up other issues related to the clinical application of the Communication Assessment Protocol. This procedure was followed to enhance trustworthiness.

After completion of the focus group interview the facilitator and principal researcher thanked the participants for their time and contributions. The focus group participants were then provided with lunch.

Data collected in Phase Three was a combination of the questionnaire and the focus group discussion. According to Bloor et al. (2001: 17-18) data on same topic collected by different tools deepens and enriches the understanding of the subject.

#### 4.9.5 Phase Three data analysis

The data were analyzed to determine the acceptability of the Communication Assessment Protocol by the speech-language therapists and audiologists. Both quantitative and qualitative data analysis was used during Phase Three.

There were three respondents to section II of the questionnaire; therefore description of their responses in a tabular form was more appropriate than using descriptive statistics or factor analysis. The responses to both closed and open-ended questions were analyzed qualitatively.



Content analysis of participants' viewpoints and emerging themes (Maxwell & Satake, 2006: 262) formed the basis for the topic guide for the focus group discussion.

Supplementary information concerning applicability and acceptability of the Communication Assessment Protocol gathered by holding the focus group discussion was transcribed in detail by an independent rater using the audio recordings (Bloor et al., 2001: 59). The principal researcher studied the data in detail by reviewing the video recordings and listening to the audio recordings in addition to reading the transcripts to carry out content analysis. The content of the focus group discussion was unstructured and needed to be converted into specific units of information that were analyzed by the researcher (Stewart & Shamdasani, 1990: 108). The data were converted to manageable form by indexing manually and bringing under one heading all data relating to a particular theme (Bloor et al., 2001: 72). The principal researcher viewed the video recording, listened to the tapes and reviewed the transcripts of the focus group discussion. Key phrases and words were highlighted by the principal researcher in the transcript to be used as direct quotes when interpreting the findings of the focus group session. Perspectives of the participants were analyzed and shaped into a general description, as in a phenomenological approach (Creswell, 2003: 194). The transcript of the focus group discussion is included as Appendix IX and the recordings are also available for verification. The interpretation of the text data from the focus group discussion is presented in the chapter on results and discussion.



## 4.9.6 Phase Three validity, reliability and trustworthiness

A quantitative research method was employed during the self-administered questionnaire. Validity of the data collection tool namely the questionnaire for the speech-language therapists and audiologists was ensured by preparing section II of the questionnaire (Appendix VIII) specifically according to the objective of Phase Three. The questionnaire was based on Streicher's (2005) previously tested questionnaire. The study targeted a very specific population of speech-language therapists and audiologists in the public health sector of Mauritius.

The reliability of a study as stated during Phase Two refers to the consistency with which the measuring instrument yields a certain result (Leedy & Ormrod, 2005: 29). The questionnaire provided concise and simple instructions and the questions were straightforward to obtain the perceptions of the therapists. The method of triangulation was employed whereby the speech-language therapists and audiologists responded to the questionnaire after conducting assessments on children with CL/P. They subsequently participated in a focus group discussion to express and discuss their views.

The following strategies depicted in Table 4.16 were applied to account for the trustworthiness of the data from Phase Three.



**TABLE 4.16 Trustworthiness of Phase Three** 

Trustworthiness	Strategy
Credibility	Multi method triangulation: namely questionnaire survey and focus
	group discussion (Leedy & Ormrod, 2005: 99) was applied during data
(De Vos et al.,	collection to evaluate the acceptability of the Communication
2005: 346)	Assessment Protocol
	During the focus group discussion, video and audio recordings were
	made (Stewart & Shamdasani, 1990: 16). A transcript of the audio
	recording was also made.
	A facilitator was used to limit any biases by the principal researcher
	(Stewart & Shamdasani, 1990: 17).
	Member checking by the facilitator after discussion of each topic for
	clarifications further ensured the credibility, as data was not open to
	misinterpretations.
	An in depth description of the setting and participants for the focus
	group session was provided so that the reader can judge the credibility
	of this phase of the study (Creswell, 2001: 196).
Transferability	Systematic description of Phase Three to evaluate the acceptability of
	the Communication Assessment Protocol was provided such that any
(De Vos et l.,	investigator could judge the degree of transferability to another context.
2005: 346)	The researcher involved all speech-language therapists and audiologists,
	in the evaluation process. They had conducted assessments on children
	with CL/P. They were also the end users of the Communication
	Assessment Protocol. Their opinions and views individually and as a
	group formed the basis for determining the acceptability of the protocol.
Dependability	The concept of replication was problematic during this phase as the four
<i>-</i>	speech therapists and audiologists assessed many children with CL/P.
(De Vos et al.,	However, they participated in the evaluation of the Communication
2005: 346)	Assessment Protocol by sharing their experiences, to corroborate,
~	elaborate and illuminate the research topic (De Vos et al., 2005: 311)
Confirmability	The four speech-language therapists and audiologists; working in the
D.W.	public health sector of Mauritius, conducted the Communication
De Vos et al.,	Assessment Protocol using the same form and methodology.
2005: 347)	A combination of digital audio and video recordings was made for
-	confirming the views expressed by the participants.



#### 4.10 CONCLUSION

The research addressed the development of a Communication Assessment Protocol for young children with CL/P that is relevant to the clinical work conducted by speech-language therapists and audiologists in the Mauritian context. The description of the children with CL/P showed that the study sample was representative of the different types of cleft and included children with syndromes. Researchers are cautioned against combining these two groups due to their inherent differences. However, the aim of the compilation of the Communication Assessment Protocol was to provide a generic assessment tool that needs to accommodate all children with CL/P. The background information of each child that was gathered assisted in the compilation of a database for children with CL/P. Furthermore the description of characteristics of the children with CL/P in Mauritius, guided the development of a functional and authentic Communication Assessment Protocol. The participation of the speech-language therapists and audiologists, their training in the tool's administration, and the clinical experience of conducting the assessments according to the protocol contributed to the evaluation of the protocol's applicability and acceptability.

#### 4.11 SUMMARY

The main aim and objectives of the research were described and the rationale for selection of mixed methods approach was provided. The ethical principles for conducting research were addressed and applied from the beginning of the research.



The empirical research was conducted in three sequential phases. Phase One provided data that described characteristics of the children with CL/P and were the underpinnings for initiating of a database and the development of the Communication Assessment Protocol. The second phase was descriptive. The steps taken to compile the protocol, the pilot study conducted, the data collected and analysed were described in detail. The speech-language therapists and audiologists in Mauritius participated throughout the research process and in Phase Three, they participated to discuss the clinical applicability and acceptability of the protocol.