

**A training programme  
to facilitate  
parents' orientation to and definition of problems  
experienced in parenting young children with  
moderate to severe communication disabilities**

by

**Legini Moodley**

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**SUPERVISOR: Prof. CJE Uys**

**CO-SUPERVISOR: Prof Erna Alant**

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**This dissertation is dedicated to...**

**My late parents, and**

**My dearest son, Pirolan.**

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## Abstract

Effective, sustainable and versatile Early Childhood Intervention (ECI) requires collaborative problem-solving between parents as help-seekers and professionals as help-givers during assessment, to facilitate treatment planning based on mutual understanding of parents' problems and needs. However, international and South African research reflect parent dissatisfaction and poor participation in ECI programmes for young children with disabilities, which indicates a breakdown in the collaborative problem solving process. The field of ECI confronts the problem by training professionals as help-givers, but does not do the same for parents as help-seekers. This study drew from the field of psychology and innovatively used the first two stages of social problem-solving, namely, problem orientation and problem definition to conceptualise help-seeking in Early Childhood Communication Intervention (ECCI). The study developed and tested a parent training programme to facilitate parents' orientation to and definition of problems experienced in parenting young children (0-6 years) with moderate to severe communication disabilities. A quasi-experimental non-equivalent groups pre-test-post-test control group design was used to implement 16 hours of training with 34 parents (i.e. 15 in the experimental group and 19 in the control group). Between-group and within-group analyses revealed that training had a statistically significant effect on parents' problem orientations regarding initial and maintaining attributions of children's established disabilities, confidence in seeking help from family and friends, and appraising problems as challenges. Training effects were even greater for problem definition with parents showing moderately good skills in providing relevant information in an organized format, thereby facilitating intervention planning. Theoretical and clinical implications of the findings are discussed.

*Keywords:* collaborative problem-solving, problem orientation, problem definition, parent communication, parent training, help-seeking, empowering, family-centred intervention, parent coping, adaptation and positive functioning, health literacy.

## CHAPTER 1

### PROBLEM STATEMENT AND RATIONALE

#### 1.1 Introduction

This chapter presents the background to the study by describing the research problem and the rationale for the study. The terminology is defined as applied in the dissertation, and the abbreviations are listed. A brief outline of the content of chapters is also presented.

#### 1.2 Problem statement and rationale

Parenting young children with disabilities is a challenging and frequently stressful experience for many parents (Barnett, Clements, Kaplan-Estrin, & Fialka, 2003; Families Special Interest Research Group of IASSID, 2012). Both internationally and nationally, the challenges are compounded for parents of children with moderate to severe disabilities who come from culturally diverse backgrounds and live under adverse physical, social, health and economic conditions. Such conditions are common in developing countries like South Africa (Emmet, 2005; McConkey, 1995; Saloojee, Phohole, Saloojee, & IJsselmuiden, 2007; Hwenha, 2014).

Prevalence data for young children with disabilities is a challenge to establish in most countries world-wide (World Health Organization, 2011). The statistics for South African children varies greatly due to differences in the definition of disability and measuring instruments used. This variance in data is illustrated in a report compiled by the South African Department of Social Development (DSD), Department of Women, Children and People with Disabilities (DWCPD) and UNICEF in 2012. Local small-scale child disability surveys from 1992-2002 identified 1.1% to 7% of children with disabilities; the only population-based national disability survey commissioned by the Department of Health in 1999 reported that 1.6% of children in the age-range 1-5 years presented with moderate to severe disabilities; and the general household survey in 2009 classified almost 2.1 million children (i.e. 11.2% of the total child population) as disabled (DSD, DWCPD, & UNICEF, 2012). The population census data for 2001 from Statistics South Africa (2001) reported 474 000 children with severe disabilities. However, the Census 2011 data as well as the General Household Surveys from 2009 to 2014 only reported on individuals aged 5 years and older (Statistics South Africa, 2014b). Disability

prevalence figures ranged from 7.5% in Census 2011 to 4.9% in the 2014 General Household Survey (Statistics South Africa, 2014b). Despite the variability, the data clearly illustrate that a large number of South African children present with disabilities. Research indicates, though, that these children received inadequate support from the health, education and social welfare sectors; and that the experience of caregivers of children with severe disabilities was that of despair and hopelessness (Saloojee et al., 2007; Samuels, Slemming & Balton, 2012). The country's National Development Plan (National Planning Commission (NPC), 2011, p. 269) reveals that South Africa was "one of the 20 countries with the highest burden of under-nutrition", and that "2.8 million households and 11.5 million individuals" were "vulnerable to hunger...". The National Development Plan also recognizes that early childhood development was "one of the most underdeveloped sectors of education", and it highlights the critical need for postnatal support for vulnerable caregivers (NPC, 2011, p. 279).

Parents of young children with disabilities are vulnerable and various demands contribute to increased parenting stress. Some of these demands are high care-giving responsibilities and, consequently, reduced time for personal and family goals. The situation is exacerbated by increased financial expenditure on specialized medical care and equipment; difficulty in managing relationships with family and professionals; and dealing with family and community perceptions of disability (Harris & McHale, 1989; Singer & Irvin, 1989; Erickson & Upshur, 1989; Beresford, 1994; McConkey, 1995; Carpenter, 2000; Cho, Singer, & Brenner, 2000; Saloojee et al., 2007; Families Special Interest Research Group of IASSID, 2012). To cope, parents often seek help from family and friends in informal social networks to obtain instrumental (e.g. information and materials) and/or affective support. When the required support is inadequate for addressing their needs, parents seek help from professionals in formal social networks (e.g. speech-language therapists (SLTs) at public hospitals) to access specialized support from fields such as Early Childhood Intervention (ECI).

The specialized assistance of ECI professionals is critical in enabling parents and families to adapt and integrate the child in sustainable and meaningful ways into the family's daily routine, congruent with the individual needs of all family members (Gallimore, Weisner, Bernheimer, Guthrie, & Nihira, 1993). Parent competence in accessing the specialized help required from professionals is thus the key focus of this research project. In this study, young children (0-6 years) with moderate to severe communication disabilities that are secondary to established

disabilities is the population selected to contextualize the need for parent competence in seeking help. The children's communication disabilities in addition to cognitive, motor and/or psychosocial disabilities create significant challenges that require parents to access specialized support from ECI professionals (Rossetti, 2001; Families Special Interest Research Group of IASSID, 2012). Prevalence data for South African children with moderate to severe communication disabilities that are secondary to established disabilities are not available. However, the latest census data from Statistics South Africa (2011) revealed that 1.6% or approximately 800 000 South Africans older than 5 years present with mild to severe communication disabilities. Parents continue to seek and rely on the expertise of professionals for specialized care as the child grows older and day-to-day parenting responsibilities related to their roles as caregiver, consumer, decision-maker and trainer increase (Beresford, 1994; Rossetti, 2001; Granlund, Björk-Åkesson, & Alant, 2005). Parents' competence in seeking help is therefore an important coping resource, and constitutes a crucial aspect in the emerging field of health literacy (Hentz & Ellis, 2010; Kickbusch, Pelikan, Apfel, & Tsouros, 2013). Their competence facilitates their initial and sustained access to much needed formal support to meet parenting demands (Brickman et al., 1982; Hill, 2011). The goal of enhancing positive functioning in the child, parent and family is central to formal support programmes in ECI, such as Early Childhood Communication Intervention (ECCI) (Singer & Irvin, 1989; Dunst, Trivette, & Deal, 1998; 1994a; Dunst, 2004).

Early Childhood Intervention and ECCI are broadly conceptualized as help-seeking and help-giving exchanges between parents as help-seekers and professionals as help-givers (Dunst et al., 1988). The field of ECI defines the help-giving process from the professional's perspective (Dunst et al., 1988; 1994a), but pays limited attention to the help-seeking aspect from the parent's perspective. The concept of help-seeking in ECI is therefore underspecified. Drawing from the work of Dunst, Trivette, Gordon, and Pletcher (1989, p. 125) on mobilizing informal family support networks in ECI, and the analysis of help-seeking behaviour in the field of nursing (Cornally & McCarthy, 2011), help-seeking from formal social support networks such as ECI may be conceptualised as the parent's perception "...of a problem and the need for assistance..." and the communication of the problem and need to professionals to access the needed help; whilst help-giving refers to professionals providing the support that the parent needs. This exchange is further conceptualised from a family-centred paradigm in ECI, and is

operationalised as a collaborative problem-solving process between both participants (Coufal, 1993; Björk-Åkesson, Granlund, & Olsson, 1996; Granlund, Björk-Åkesson, & Alant, 2005). A family-centred paradigm is derived from a theoretical framework of ecology, social systems and empowerment and as such is consumer driven with a particular emphasis on competence enhancement (Dunst et al., 1988; Dunst & Deal, 1994a; Dempsey & Keen, 2008). Intervention is responsive to concerns and needs that families identify during assessment, rather than those identified by professionals; the family's choice, decision-making and control over intervention are central (Dunst et al., 1988, 1994a; Björk-Åkesson & Granlund, 1995; Dempsey & Keen, 2008). During assessment, professionals support families in organizing their thoughts and perceptions of the problematic situation to ascertain solutions for identified concerns (Bryant, 1984; Dunst et al., 1988; Bagnato, 2007). Collaborative problem-solving is the mechanism used to describe the latter process and is defined as an interactive process between parent and professional to reach mutual understanding of problems and needs as defined by parents, in such a way that both participants contribute to generating relevant solutions (Coufal, 1993). The collaborative relationship between the parent as help-seeker and professional as help-giver as well as the consultative process of problem-solving are therefore core features that influence positive intervention outcomes (Coufal, 1993).

The process of collaborative problem-solving unfolds based on a few implicit assumptions regarding the competencies of parents/families and professionals as help-seekers and help-givers respectively. Firstly, that the family wishes to solve the problem and that they have the capacity to solve their own problems (Bryant, 1984; Dunst et al., 1988, 1994b; Dunst, 2004). Parents are therefore viewed as active participants in the process (i.e., they have control over the intervention process); as such, they are capable of identifying concerns and needs and are also capable in mobilizing and procuring support and resources to meet those needs (Dunst et al., 1994b; Dunst, 2004). Secondly, professionals are able to work collaboratively with parents in enhancing parents' capacity to identify concerns and needs, in order that intervention plans address the concerns and needs identified by parents (Granlund et al., 2005). The latter scenario describes the ideal context for collaborative problem-solving between parents and professionals to achieve successful intervention outcomes. Interventions are deemed successful when parents are able to access the support they need in parenting young children with disabilities in their daily context (Gallimore et al., 1993; Rossetti, 2001; Alant, 2005a).

However, parents' dissatisfaction with interventions that do not address their needs is a common problem reported in the ECI literature (McConkey, 1995; Dunst et al., 1988; Dunst & Deal, 1994a; Björk-Åkesson & Granlund, 1995; Sloper, 1999; Bruder, 2000; Nijhuis, Reinders-Messelink, de Blécourt, Boonstra, Calamé & Groothoff, 2008). It implies that the collaborative problem-solving process may not be occurring as envisaged; and this may explain parents' inability to access intervention that meets their needs. One way of establishing possible causes of the problem is to revisit the reliability of the core assumptions that underpin effective collaborative problem-solving, specifically the competencies of parents and professionals. If the assumptions of either participant cannot be taken for granted, it is imperative that appropriate support mechanisms are identified and mobilised to facilitate effective intervention outcomes.

A review of the ECI literature has established unease about the capacity of both parents and professionals to engage competently in the collaborative problem-solving process. From the perspective of professionals' competence, research found that many professionals were not skilled in working within a family-centred paradigm that would ensure that their intervention met the concerns and needs identified by family, rather than those of the professional (Dunst et al., 1988; 1994a; Björk-Åkesson & Granlund, 1995; Sloper, 1999; Bruder, 2000; Mueller, Singer & Draper, 2008). This results in intervention that does not address parents' concerns and needs, but rather contributes to parent dissatisfaction and poor participation during ECI.

Two critically important issues may compromise parents' ability to identify and communicate concerns and needs to professionals effectively enough to facilitate successful and sustainable intervention outcomes. The first compromising factor is parents' emotional state during help-seeking, since they are often in a stage of shock, trying to cope and adapt to the demands associated with having a child with a disability (Singer & Irvin, 1989; Rossetti, 2001). Secondly, parents often show a lack of competence in communicating their problems and needs effectively when accessing intervention (Levasseur & Carrier, 2010). The latter is significant when parents try to raise their concerns and there is a mismatch between them and the professionals' cultural, linguistic, social and economic backgrounds, and when their levels of education and literacy are low (McConkey, 1995; 2005; Krause, 1997; Alant, 2005b; 2007; Hill, 2011; Levasseur & Carrier, 2010; Schmidt von Wühlisch & Pascoe, 2010).

Dunst et al. (1988, p. 60) defined concerns as “conditions that lead to a recognition that the difference between what is and what ought to be is sufficiently disparate to warrant attention”,

whilst needs were defined as “conditions that lead to a recognition that something (i.e., a resource) will reduce the discrepancy between what is and what ought to be.” The authors further state that “concerns produce discrepancies whereas need recognition and resource procurement (solution identification) reduce discrepancies” (Dunst et al., 1988, p. 60). Given this background, Dunst et al. (1988) indicated that families may not clearly state exactly what their needs are but may instead describe their concerns or the problem as they see it. In contrast, Björk-Åkesson et al. (1996) felt that parents might express their needs by describing resources that they require to resolve problems, instead of describing the problems/concerns that the resources are intended to solve. Professionals interpret the needs as problem descriptions and develop interventions based on the requested resources, only to have parents complain that the interventions do not address their needs (Carlhed, Björk-Åkesson, & Granlund, 2003).

The above discussion clearly demonstrates that, in collaborative problem-solving, factors related to competencies of both the parent and the professional may contribute to the clinical problem of parents’ dissatisfaction with intervention that did not meet their needs. To date, in the field of ECI, the solution is pursued largely from the point of providing professional/help-giver support in developing competencies that embrace the shift from traditional professional-centred to family-centred help-giving styles. These interventions support the current conceptualization of ECI and family support as an integrated endeavour (Sloper, 1999; Dunst, 2004). Hence, increasing professionals’ competencies in giving help is the strategy used to facilitate both the help-seeking and help-giving exchange between parent and professional. Dunst et al. (1988) highlighted the need for professionals to be aware of the difference between concerns and needs during assessment. Professionals should promote the family’s/parents’ capacity to clarify concerns in such a manner that the nature of needs and specific resources that meet these needs are identified to promote effective intervention planning. Research and intervention responded with the development of methods for gathering information, namely, interviews, observations and need-based measurement scales, or a combination of these (Dunst et al., 1988; Dunst & Deal, 1994b). These methods enabled professionals to assist parents in clarifying concerns and needs in order to effect an alignment in parents’ descriptions of concerns, needs and resources, thereby maintaining a focused approach to the collection of information. The assumption was that such an alignment would enable professionals to develop a good understanding of the families’ concerns and needs, thereby enhancing effective help-giving (Dunst et al., 1988).

Examples of measurement tools included the Parent Needs Inventory by Fewell, Meyer and Schell (1981, cited in Dunst et al., 1988), the Family Resource Scale by Dunst & Leet (1987), and the Family Strengths and Needs Assessment (Oregon Department of Human Services, 2014).

In a review and integration of the literature on help-seeking in ECI, Dunst et al., (1988) emphasized help-giver behaviours that could have harmful or positive outcomes; and one of the conclusions from the review related to non-contingent help-giving. Dunst et al. (1988, p. 37) described the latter as help-giving that “does not require the recipient to acquire effective behavior and thus renders the person...dependent, the immediate needs of the person may be met, but the ability to teach and foster effective behaviors are diminished.” A critical evaluation of the current methods of information gathering in ECI broadly, reflects elements of non-contingent help-giving which fosters dependence in parents (Fisher, Nadler, & DePaulo, 1983; Dunst, et al., 1988; Dunst, et al., 1989). These methods prevent parents from building on current communication strengths in providing information and acquiring the specific perceptions, knowledge and skills that facilitate the communication of concerns and needs in ways that enhance effective and sustainable intervention planning and outcomes. This highlights the fact that the current focus on help- giving and the process of gathering information embedded in current tools may unintentionally function to limit parents’ capacity to develop as independent, self-sustaining help-seekers. The challenge is therefore to have an integrated, balanced approach to the facilitation of collaborative problem-solving by empowering professionals as help-givers as well as parents as help-seekers.

This study addressed the limited attention given to empowering parents’ skills in seeking help in specific ways that give them greater independence and control during the helping relationship in ECCI (Brickman et al., 1982; Levasseur & Carrier, 2010; Hill, 2011). While the current theoretical models of collaborative problem-solving provide a general framework for help-seeking and help-giving, the focus remains largely on enhancing the competence of professionals as help-givers (Coufal, 1993; Dunst et al., 1988; 1994a; Björk-Åkesson et al., 1996; Dunst, 2004). Scant attention is given to the specific perceptions, knowledge and skills that would enhance the competence of parents as help-seekers. The need for speech-language therapists (SLTs) to take a more active role in this regard is supported at three levels. Firstly, the emerging field of health literacy recognizes the unique expertise of the SLT in the areas of language, communication, culture and cognition; and advocates strongly for SLTs to play a

greater role in supporting individuals to access and utilize health care services effectively (Hentz & Ellis, 2010). Secondly, recognition of SLTs as members of the mental health team and their role in promoting the well-being of individuals with communication and swallowing disabilities, and their families—is evolving (South African Speech-Language-Hearing Association, 2015; Irish Association of Speech and Language Therapists, 2006). Thirdly, the significant role of the SLT in health promotion, prevention and advocacy, education and research is acknowledged in the scope of the profession internationally and nationally in South Africa (American Speech-Language-Hearing Association, 2007; Department of Health, in press). However, active involvement of the profession in this regard is inadequate at national and international levels, based on the limited research evident in the literature (Schmidt von Wühlisch & Pascoe, 2010; Hill, 2011). Therefore, this study charts a way forward in relatively new research territories for the profession of Speech-Language Therapy. The study draws from the field of psychology and uses a problem-solving approach to strengthen parents' competence as help-seekers. The approach was initially proposed by D'Zurilla and Goldstein in 1971, and revised over the years by D'Zurilla (D'Zurilla & Nezu, 1982; D'Zurilla, 1986; D'Zurilla & Nezu, 1999, 2010). This study innovatively uses the first two stages of social problem-solving, namely problem orientation and problem definition, to provide a relevant, systematic, evidence-based framework to conceptualise, operationalise, implement and evaluate a parent support programme to facilitate parents' help-seeking in ECCI.

### **1.3 Terminology**

The following terms are defined according to their use in this dissertation.

*Adaptation:* "...an on-going process whereby parents are able to sensitively read and respond to their child's signals in a manner conducive to health development" (Barnett et al., 2003, p. 184).

*Adverse context:* High risk, impoverished physical and social conditions that do not facilitate the developmental and healthy functioning of child and family, such as poverty, chronic illness, catastrophic life events, trauma, loss and abuse (Walsh, 2003, p. 2). The focus in this study is on parents and families from low socio-economic backgrounds.

*Competence:* This term refers to parents having (or not having) the appropriate knowledge, skills and perceptions that facilitate effective help-seeking in ECI.

*Early Childhood Intervention* refers to “services provided to young children and their families with the aim of increasing the probability that young children at risk or with established physical and/or mental conditions function and develop as well as possible.” Children’s age groups and target groups to receive services “vary between countries, although a common age span is birth to the start of school (5-7years).” (Granlund et al., 2005, p. 221).

*Early Childhood Communication Intervention* refers to early childhood intervention that is specifically provided to families and children who demonstrate a disability or delay involving communication, language, speech, or pre-requisite oral-motor behaviour (adapted from ASHA, 1989, p. 32).

*Family or Parent:* The family is a social system comprising of a group of individuals who construct their own reality (Turnbull, Turbiville and Turnbull, 2000). As families come from diverse cultural groups, Turnbull et al. (2000) highlighted the need for each family to dictate its membership and the roles assumed during functioning. Osher and Osher (2002, p. 48, cited by Granlund et al., 2005, p. 225) state that a family “...can include biological or adoptive parents as well as foster parents and their partners, siblings, extended family members (kinship caregivers), and friends who provide a significant level of care and support to a child or primary caregiver”. In this study, the term parent “...is used in a functional and not biological sense...” (Dunst, 2004, p. 6) and refers to the individual who is tasked with parenting and care-giving responsibilities for the child with a disability.

*Helping:* “...the act of promoting and supporting family functioning in a way that enhances the acquisition of competencies that permit a greater degree of intra-family control over subsequent activities” (Dunst et al., 1988, p. 7). The terms ‘help-seeker’ and ‘help-giver’ are used throughout this dissertation and respectively refer to the parent/family and ECI professional. Both terms emanate from literature on helping relationships and are used in the ECI literature as well (Fisher et al., 1983; Dunst et al., 1988; 1994a; Dunst, 2004).

*Health literacy* refers to “... people’s knowledge, motivation and competences to access, understand, appraise and apply health information in order to make judgements and take decisions in everyday life concerning health care, disease prevention and health promotion to maintain or improve quality of life during the life course.” (Kickbusch et al., 2013, p. 4).

*Help-seeking* is defined as “a problem focused, planned behaviour, involving interpersonal interaction with a selected health-care professional.” (Cornally & McCarthy, 2011, p. 280). In the context of ECI help-seeking refers to parents’ ability to recognize a problematic behaviour or situation, identify the need for assistance from informal or formal social networks and to mobilize and procure the required assistance (Fisher, et al., 1983; Dunst, et al., 1988; 1989; 1994).

*Mental health* refers to the “promotion of well being and prevention, treatment and rehabilitation of people affected by mental health disorders”, for example, depression (South African Speech-Language-Hearing Association, 2015, p. 20). In the context of this study, it refers to parents’ “social, emotional and/or behavioural functioning ...” when seeking help from ECCI, which may be influenced by “... individual and environmental factors including biological, psychological and social factors.” (South African Speech-Language-Hearing Association, 2015, p. 20).

*Need* refers to “something (e.g. a resource) that is desired or lacking but wanted or required to achieve a goal or attain a particular end. Operationally, a need is an individual’s judgment of the discrepancy between actual states or conditions and what is considered normative, desired, or valued from a help-seeker’s and not a help-giver’s perspective.” (Dunst et al., 1988, p. 13).

*Positive functioning* refers to the child’s, the parent’s and the family’s growth and development in their daily lives (Dunst et al., 1988; Dunst, 2004). In the context of this study, it relates to accessing effective, sustainable and versatile intervention to manage the child’s established and moderate to severe communication disabilities in constructive ways that promote child, parent and family well-being under adverse socio-economic conditions (Dunst, 2004; Alant, 2005a).

*Resilience*: “the ability to withstand and rebound from disruptive life challenges”.... “It involves dynamic processes fostering positive adaptation within the context of significant adversity” (Luthar, Cicchetti, & Becker, 2000, cited in Walsh, 2003, p. 1).

*Social support* refers to “the resources...provided to individuals or social units (e.g., a family) in response to the need for aid and assistance...that includes physical and instrumental assistance, attitude transmission, resource and information sharing, and emotional and psychological assistance. The persons and institutions with which a family and its members come in contact – either directly or indirectly – are referred to as the family’s personal social network, and it is this network that is the primary source of support to families and individual family members.” (Dunst et al., 1989, p. 124).

*Stress*: “...a particular type of person-environment relationship or transaction in which demands are appraised by the person as taxing or exceeding coping resources and endangering well-being” (D’Zurilla & Nezu, 1999, p. 67; Lazarus & Folkman, 1984).

#### **1.4 Abbreviations**

DSD: Department of Social Development

DWCPD: Department of Women, Children and People with Disabilities

ECD: Early Childhood Development

ECI: Early Childhood Intervention

ECCI: Early Childhood Communication Intervention

IASSID: International Association for the Scientific Study of Intellectual Disabilities

NPC: National Planning Commission

POD: Problem Orientation and Definition

SLT: Speech-language therapist

#### **1.5 Chapter outlines**

Chapter 1 introduces the background to and the motivation for the study. An explanation of important terms and abbreviations are included, as well as an outline of each chapter. Chapter 2 provides the conceptual and theoretical framework of the study by integrating parents’ help-

seeking with the social problem-solving constructs of problem orientation and problem definition. A systematic framework for analysing and supporting parents' orientation to and definition of problems is presented and relevant issues for developing, implementing and evaluating parent support programmes are considered. Chapter 3 outlines the methodology used to plan and implement the study and includes the aim, design, participants, development of material, pilot studies and the procedures for data collection and analysis. Validity and reliability issues are also considered. Chapter 4 presents the results according to the study's aim and sub-aims and confirms reliability. Chapter 5 interprets and accounts for the main findings in relation to the literature and the context of this study. Clinical implications of the findings are also considered. Chapter 6 concludes with a critical review of the strengths and limitations of the study, research implications are presented and recommendations are made for future research.

## **1.6 Summary**

This chapter provided the rationale for this study by highlighting the problem of parent dissatisfaction with intervention that did not meet their needs and the critical role that parents may play in contributing to the problem. A problem-solving approach was proposed to support parents in the role of help-seekers. Terminology that is frequently used in the study was defined and the content of each chapter was briefly outlined.

## CHAPTER 2

### PROBLEM ORIENTATION AND DEFINITION IN EARLY CHILDHOOD COMMUNICATION (ECCI): A THEORETICAL FRAMEWORK FOR PARENT SUPPORT IN HELP-SEEKING

#### **2.1 Introduction**

The support of parents in seeking help is vital to enable them to access ECI that facilitates positive functioning in the child, parent and family. The challenge, however, is two-fold: (i) placing parents' search for help within an evidence-based theoretical framework and then identifying core elements of help-seeking that are critical in achieving positive intervention outcomes and thereby parent satisfaction; and (ii) implementing support in ways that promote parents' ability to use effective help-seeking behaviours when accessing ECCI. This chapter proposes a social problem-solving approach to conceptualise and operationalise parents' help-seeking during ECCI, with a specific focus on the first two stages of social problem-solving, namely problem orientation and problem definition and formulation. The chapter critically discusses the two stages in relation to ECCI, and derives the core content that parent support programmes should include, to facilitate parents' help-seeking during ECCI.

#### **2.2 Using a social problem-solving approach to support parents who seek help in ECCI**

Parents are fundamental resources, and their positive functioning in accessing help from formal social networks to manage the challenges of parenting children with disabilities is critical in mediating positive outcomes for the child, parent and family (Barnett et al., 2003; Shonkoff & Meisels, 2000; Bagnato, Neisworth & Pretti-Frontczak, 2010; NPC, 2011). Chapter 1, however, has indicated that parents' competence in seeking help from ECI professionals cannot be taken for granted and may be a factor contributing to interventions not meeting parents' needs, thus highlighting the need for parent support. Dunst's (2004) broad-based integrated framework for practicing ECI and family support constitutes the overall theoretical framework for this study for the following two reasons that are widely endorsed in the ECI literature (Sloper, 1999; Singer & Irvin, 1989; Zinkin & McConachie, 1995; Davis & Rushton, 1991; Shonkoff & Meisels, 2000; Saloojee et al., 2007). Firstly, parent/family support and capacity building are identified as the

principle means of strengthening the child's functioning and are particularly relevant for families from diverse cultures living in developing contexts. The integrated framework of child and family support is endorsed by South Africa in the National Integrated Plan for Early Childhood Development (UNICEF, 2005). Secondly, parent-professional collaboration that embodies the five principles of promotion, empowerment, strengths-based, resource-based and family-centred, is identified as crucial in supporting parents and families. This section motivates for the selection of social problem-solving, specifically problem orientation and problem definition and formulation, as the central theoretical framework to support parents in seeking help from ECCI.

### **2.2.1 Contextualizing parents' help-seeking and social problem-solving**

The main argument of this section is the conceptualisation of help-seeking as a coping strategy that involves parents' use of their social problem-solving skills. The theoretical association between parent's help-seeking and problem-solving has received minimal attention in the field of ECI, despite the fact that parents provide crucial information during help-seeking that constitutes the foundation of intervention programmes. The nature and reliability of information that parents present as providers of information has not yet been investigated as a contributing factor to poor intervention outcomes, including parents' satisfaction with services. The following section illustrates the relationship between parents' help-seeking and social problem-solving.

The theoretical origins of stress, coping and social problem-solving are firmly entrenched in the psychology literature, but for many years the concepts of stress and coping were perceived in isolation from that of social problem-solving (Lazarus & Folkman, 1984; D'Zurilla & Nezu, 1982; D'Zurilla & Nezu, 1999, 2010). The current integrated problem-solving model of stress recognises the conceptual overlap in the three areas and identifies problem-solving as a general coping strategy in managing stressful situations (D'Zurilla & Nezu, 1999, 2010). In applying the latter theory to ECI, the birth and care of a child with disabilities are construed as major stressful events that create demands that often exceed parents' coping resources at a personal, social, or biological level (D'Zurilla & Nezu, 1999). The disability also creates daily situational problems such as feeding and communication (Rossetti, 2001), which were highlighted in Chapter 1. Research suggests that daily situational demands have a far greater effect on parents'

psychological and physical well-being compared to the diagnosis of an established disability itself (Singer & Irvin, 1989; D’Zurilla & Nezu, 1999, 2010).

Individual’s responses to stressful experiences could be explained by two key constructs, namely cognitive appraisal and coping (Lazarus & Folkman, 1984). For parents of children with chronic disabilities, cognitive appraisal refers to their evaluation of the disability as a threat or challenge, whilst coping refers to parents’ use of different cognitive and behavioural activities to manage the stressful situational and emotional demands (Lazarus & Folkman, 1984). Problem-focused coping strategies are used to manage stressful situational demands, and emotion-focused coping strategies are used to manage the emotions generated by parents’ cognitive appraisals (D’Zurilla & Nezu, 1999, 2010). Research indicates that problem-focused coping strategies dominate when stressful events are appraised as changeable or controllable (e.g. parent believes that the child’s communication disabilities can be improved), whilst emotion-focused coping strategies prevail when conditions are appraised as unchangeable or uncontrollable (e.g. parent believes that the child’s communication disability cannot be improved) (D’Zurilla, 1986; D’Zurilla & Nezu, 1999, 2010). Research indicates that most parents utilize both types of coping strategies to varying degrees during stressful situations (Lazarus, 2000; Sloper, 1999).

From the theoretical perspective described, help-seeking is conceptualised as a problem-focused coping strategy that parents use to obtain the help needed to manage the situational and emotional demands of parenting children with disabilities effectively (Brickman et al., 1982; Beresford, 1994; Cornally & McCarthy, 2011). However, parents’ cognitive appraisals of factors such as the diagnosis, the chronic nature of the child’s disability and the consequent emotional effect these have in the context of other competing demands (e.g. poverty) are critical in mediating parents’ positive or negative coping. The nature of parents’ coping would have a significant effect on parents’ motivation and capacity to seek help effectively (D’Zurilla & Nezu, 1999, 2010). For example, parents who cope positively would actively seek help, since they believe that solutions are available, while parents who cope negatively are unlikely to seek help, since they either deny the existence of problems or believe that solutions are not available to support the child and family (D’Zurilla & Nezu, 1999, 2010). Folkman, Schaefer, & Lazarus (1979) identified problem-solving as a critical coping resource, which implies that parents’ problem-solving skills underpin and thereby influence their use of positive or negative

behaviours in seeking help. Thus, parents' help-seeking skills are a significant indicator of their problem-solving skills and therefore, of their coping and positive functioning.

Despite recognising parents' effective functioning as a critical mediator of positive intervention outcomes for the child and family (Barnett et al., 2003; Singer & Irvin, 1989; Dunst, 2004), models of collaborative problem-solving in ECI pay limited attention to the fact that parents use their social problem-solving skills as a coping strategy when participating in collaborative problem-solving. As such, parents' positive or negative coping would influence the quality of information provided for intervention planning.

The literature in ECI reflects a trend toward assessing and supporting parents' coping and positive functioning (Dunst, 2004; Sloper, 1999; NPC, 2011), but current practices remain fragmented and lack a systematic, evidence-based approach. The preceding theoretical argument highlights parents' social problem-solving as a basic element that mediates their effective functioning as help-seekers (D'Zurilla & Nezu, 1999, 2010). Rivera, Schewchuk, & Elliott (2003) highlighted three important issues that emphasise the need for supporting parents' problem-solving skills, namely, (i) rehabilitation does not adequately prepare caregivers to negotiate the challenges of parenting children with chronic disabilities and some challenges are mediated by the effectiveness of caregivers' problem-solving skills (e.g. pressure sores); (ii) caregivers' problem-solving skills are better predictors of depression than social support; and (iii) training in problem-solving is effective in the treatment of depression, promotes self-management and is cost effective in the long-term. This study therefore proposes using the theoretical framework of social problem-solving to identify and support specific problem-solving skills that are critical in promoting parents' effective help-seeking in ECCI.

### **2.2.2 Theoretical framework of social problem-solving: identifying critical behaviours that underpin parents' help-seeking in ECCI**

The theoretical framework of social problem-solving in the discipline of psychology was developed by D'Zurilla and Goldfried (1971), and was expanded and refined over the years following significant research to establish validity (D'Zurilla & Nezu, 1982; D'Zurilla, 1986; D'Zurilla & Nezu, 1999, 2010). The framework is utilized extensively in research and practice in the fields of clinical and counselling psychology (Heppner, 1978, Durlak, 1983; D'Zurilla, 1986;

Heppner & Peterson, 1982; D’Zurilla & Nezu, 1999, 2010) and is currently emerging in the field of rehabilitation (Coufal, 1993; Elliot, 1999; D’Zurilla & Nezu, 2010; Grant & Whittel, 2000; Heppner & Lee, 2002). The latter developments provide strong empirical support for the framework’s theoretical validity. This study extends its use to the field of ECI, specifically in the area of parents’ help-seeking in ECCI. In this section, the theoretical framework of social problem-solving is described from the psychology literature, with key terminology defined and applied broadly to ECI. The first two stages of problem orientation, and problem definition and formulation are identified as relevant constructs to operationalise and support parents’ effective help-seeking in ECCI.

Social problem-solving describes problem-solving within natural social environments and is therefore the term used in this study to describe parents’ help-seeking from ECCI contexts, such as hospitals (D’Zurilla & Nezu, 2010; Rossetti, 2001). It is viewed as one set of social skills that is important for individuals’ social competence to access help for encountered problems (D’Zurilla & Nezu, 1999, 2010). Social competence is an important factor that prevents or buffers against negative life experiences that cause psychological distress or psychopathology. Deficiencies in problem-solving skills are identified as significant contributors to ineffective coping and social competence (D’Zurilla & Nezu, 1999). Figure 1 summarizes the relationship between parents’ help-seeking in ECI broadly, and the social problem-solving process described in psychology.

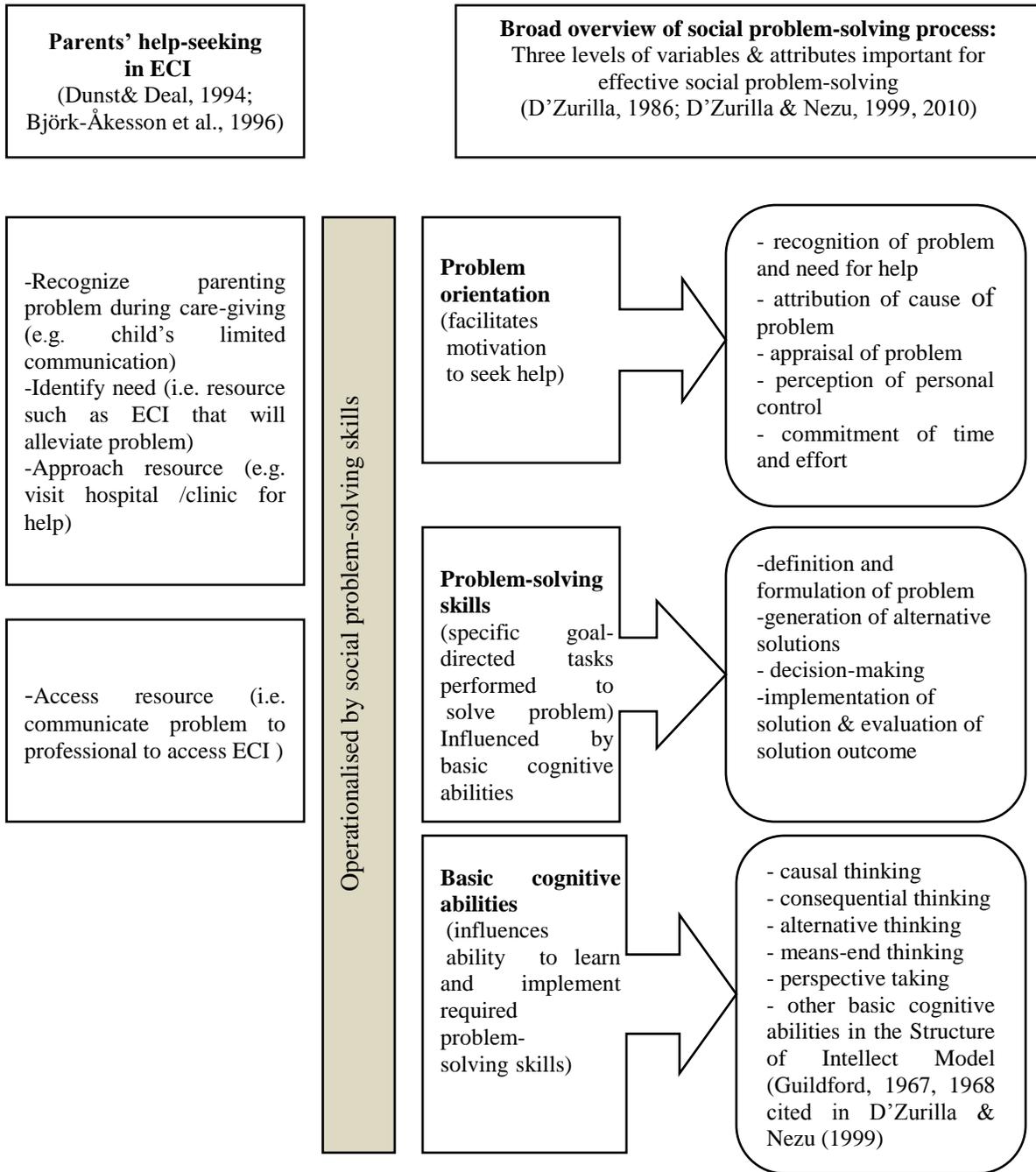


Figure 1. Parents' help-seeking in ECI and social problem-solving

Social problem-solving is defined as a “self-directed cognitive-behavioural process by which a person attempts to identify or discover effective or adaptive solutions for specific problems encountered in everyday living”; it involves conscious, rational, effortful and purposeful activity (D'Zurilla & Nezu, 1999, p. 10). As illustrated in Figure 1, the concept describes parents' decision-making to seek help from professionals to cope with the demands of

parenting young children with communication and other established disabilities (Beresford, 1994; Singer & Irvin, 1989; Dunst & Deal, 1994a; Björk-Åkesson et al., 1996). Based on the ECI literature, parents' decision-making maybe perceived broadly as four help-seeking behaviours, namely recognising parenting problems, identifying ECI as a resource that could alleviate problems, approaching ECI professionals at clinics or hospitals, and communicating information about problems and needs to access the help required (Dunst & Deal, 1994a; Rossetti, 2001).

The theory of social problem-solving defines a problem or problematic situation as “any life situation or task (present or anticipated) that demands a response for adaptive functioning, but no effective response is immediately apparent or available to the person due to the presence of ... obstacles. Such obstacles...include novelty, ambiguity, unpredictability, conflicting stimulus demands, deficiencies in performance skills, or lack of resources.” (D’Zurilla & Nezu, 1999, p. 11). This definition was formulated from a relational viewpoint and suggested that problems were individualistic, with a specific relationship between the demands of the environment on the ability of the person who is to cope with them (D’Zurilla & Nezu, 1999). According to D’Zurilla (1986), difficult problems are stressful as these involve conflict, uncertainty, and/or perceived uncontrollability. From an ECI perspective, the concept of problem or concern refers to parents' perceptions of a discrepancy between current and desired/expected functioning in parenting children with disabilities, due to one or more of the following: (i) negative perceptions of the child's communication and established disabilities, (ii) limited knowledge and parenting skills to meet the unique, unpredictable and conflicting demands of the disability; and/or (iii) lack of essential resources to facilitate adaptive parenting (i.e. financial, social) (Björk-Åkesson et al., 1996; Dunst & Deal, 1994b; Singer & Irvin, 1989; Beresford, 1994; Rossetti, 2001; Saloojee et al., 2007; Hwenha, 2014). The ECI literature reveals that parents' personal, socio-cultural and financial resources play a significant role in mediating adaptive parenting (Singer & Irvin, 1989; Dunst et al., 1994a; Saloojee et al., 2007; Hwenha, 2014). To manage care-giving demands that exceed parents' capabilities and resources, parents need to use their social problem-solving skills as a coping resource when seeking help.

Finally, a solution is defined as “a situation-specific coping response or response pattern (cognitive and/or behavioral) that is the product or outcome of the problem-solving process when

it is applied to a specific problematic situation.” (D’Zurilla & Nezu, 1999, p. 12). An effective solution varies for individuals, with changes made to the situation and/or the person’s emotional reactions so that it is not perceived as problematic any longer. The effectiveness of a solution is also dependent on the norms, values, and goals of the problem solver and those judging the outcome (D’Zurilla & Nezu, 1999). The concept of solution or needs in ECI relates to parents’ recognition that a resource (e.g. intervention, information, money, etc.) will reduce the discrepancy between parent, child and family’s current and desired functioning (Dunst et al, 1988). Dunst et al. (1988, p. 60) also stated that “concerns produce discrepancies whereas need recognition and resource procurement (solution identification) reduce discrepancies”, thus highlighting the need to clearly differentiate between the two concepts during collaborative problem-solving. Parents’ identification of ECI as a resource that will resolve parenting problems by promoting adaptive functioning in the child, parent and family is an outcome of parents’ individual problem-solving (Dunst et al., 1994a; D’Zurilla & Nezu, 1999, 2010). The latter therefore motivates and initiates parents’ help-seeking from ECI.

A definition of successful intervention is warranted in order to fully understand the concept of solution in ECI. Alant (2005a) describes successful intervention as effective, sustainable and versatile. In the context of the child’s established and communication disabilities and other associated problems that the parent may identify, effective intervention refers to positive changes arising directly from intervention received over a short period of time in the child’s communication and/or other developmental skills (e.g. motor skills) and/or associated problems such as finance. Sustainable intervention refers to maintenance of positive changes for a longer period without direct intervention, arising from the child and/or parent’s motivation to change and relevant changes made to the family’s daily environment. Finally, versatile intervention represents generic benefits gained from intervention that empowers the parent to successfully solve problems and to obtain help for similar communication problems or concerns arising in other situations, thereby enhancing the family’s overall quality of life (Alant, 2005a; Granlund et al., 2005). Parents’ skill in communicating concerns and needs is therefore the critical first step toward accessing interventions that are effective, sustainable and versatile in meeting their needs.

The preceding discussion demonstrates the importance of social problem-solving for parents who seek help from professionals in ECI. The theoretical framework of social problem-solving is subsequently described, highlighting the importance of the first two stages of problem orientation and problem definition and formulation in providing a systematic framework to conceptualise and support such parents' help-seeking specifically during ECCE.

As stated, social problem-solving is viewed as a cognitive-behavioural process of finding solutions to particular problems (D'Zurilla & Nezu, 1999, 2010). The process involves variables operating at three levels, each influencing problem-solving performance differently. Figure 1 provides a broad overview of the three variables:

(i) Problem orientation is a set of orienting responses which operate at a metacognitive level, and functions to motivate problem-solving.

(ii) Four problem-solving skills operate at a performance level to ensure effective problem-solving outcomes.

(iii) Basic cognitive abilities underlie the performance level, and affect learning and implementation of problem-solving skills (D'Zurilla, 1986; D'Zurilla & Nezu, 1999, 2010).

Although studies have found non-significant or low correlations between social problem solving and intelligence, limited knowledge of the basic cognitive abilities has resulted in current research and training, targeting mainly the two levels of problem orientation and problem-solving skills (D'Zurilla & Nezu, 1999). The two levels are therefore the focus in this study.

Problem orientation describes an individual's generalized response when facing a problem; it is informed by his/her problem-solving history (D'Zurilla & Goldfried, 1971; D'Zurilla & Nezu, 1999, 2010). It includes "an attitudinal set to either recognise or ignore problems and a set of relatively stable cognitive-emotional schemas (e.g. beliefs, appraisals), which describe how a person generally thinks and feels about life's problems and his or her ability to solve them, independent of any specific problem" (D'Zurilla & Nezu, 1999, p. 14). Both sets are illustrated as attributes in Figure 1. Problem orientations generate positive emotions and motivational tendencies, which facilitate problem-solving performance; or negative emotions and avoidance tendencies, which inhibit or disturb performance (D'Zurilla & Nezu, 1999, 2010). In contrast, the four problem-solving skills describe the performance of specific goal-directed tasks that are important for successful problem-solving and each task serves a critical function in

the problem-solving process (D’Zurilla & Nezu, 1999, 2010). The four tasks illustrated in Figure 1 are problem definition and formulation, generation of alternative solutions, decision-making, and solution implementation and outcome evaluation (D’Zurilla, 1986). To summarize, problem orientations reflect individuals’ motivation to solve problems and are influenced by their functioning when confronting problems; while problem-solving performance reflects their competence in four goal-directed tasks that are critical in finding appropriate solutions.

The theory of social problem--solving integrates the two partially independent components of problem orientation and problem solving performance levels and is presented as a prescriptive model that specifies how individuals should solve problems in order to maximize the effectiveness of outcomes (D’Zurilla & Nezu, 1999, 2010). The model is operationalised as five interactive stages: (i) problem orientation, (ii) problem definition and formulation, (iii) generation of alternative solutions, (iv) decision making, and (v) solution implementation and verification (D’Zurilla & Goldfried, 1971; Maydeu-Olivares & D’Zurilla, 1996; Nezu & D’Zurilla, 1989; D’Zurilla, 1986; D’Zurilla & Nezu, 1999, 2010). Although the stages are presented in a logical sequence, movement back and forth is expected and is the norm in real settings until satisfactory solutions are found (D’Zurilla, 1986; D’Zurilla & Nezu, 1999, 2010). The literature indicates that viewing the stages in a logical sequence is relevant for research and training purposes (D’Zurilla & Nezu, 1982, 1986). Empirical support for the theoretical validity of the framework is provided in D’Zurilla & Nezu (1982; 1999; 2010) and D’Zurilla (1986). The literature emphasises the significance of the first two stages of problem orientation and problem definition and formulation in setting the critical foundation for achieving effective problem-solving outcomes (D’Zurilla, 1986; D’Zurilla & Nezu, 1999, 2010). Although both stages are vital, particular emphasis is placed on problem definition and formulation (D’Zurilla & Nezu, 1999, 2010). It is therefore clear that effective functioning of the five stages of social problem-solving is significant to achieve optimal solutions and that problem orientation and problem definition and formulation are important in maximizing effective outcomes, with the latter stage being particularly salient.

From the perspective of parents’ seeking help in ECCI, the two stages of problem orientation and problem definition and formulation are significant in operationalising parents’ help-seeking, as illustrated in Figure 1. Problem orientation centres on parents’ motivation to

seek help for problems they experience and aligns with the first three help-seeking behaviours described in Figure 1, while problem definition and formulation correlates with the fourth behaviour of parents' communicating their concerns and needs to ECI professionals. The term 'problem definition' is used hence forth in line with its reference in ECI literature (Granlund et al., 2005). The theory of social problem-solving provides a conceptual framework for the two stages, prescribing how individuals should approach and communicate problems in order to ensure optimal solutions. The next section discusses each stage critically to demonstrate relevance for parents' seeking help in ECCI, and utilizes the prescribed social problem-solving principles to propose a theoretical framework of problem orientation and problem definition to facilitate parents' help-seeking in ECCI.

### **2.3 Towards a framework of problem orientation and problem definition to facilitate parents' help-seeking in ECCI**

A theoretical framework provides a frame of reference for defining key concepts, guiding data collection and analysis, and providing an explanatory framework for interpreting empirical findings (Babbie & Mouton, 2001). The first two stages of the theory of social problem-solving, that is, problem orientation and problem definition and formulation, are used to propose a systematic, evidence-based theoretical framework to conceptualise, operationalise and support parents' help-seeking during ECCI. The two stages are discussed initially from a social problem-solving perspective to identify prescribed principles for finding effective solutions. The stages and principles are applied critically to parents seeking help in ECCI to illustrate relevance. A framework is presented of how parents should approach and communicate problems and needs to access ECCI. Particular attention is given to current ECI research that profiles parents who are coping and functioning positively in parenting children with disabilities, implying the use of effective, sustainable and versatile help-seeking skills. The research is in line with the theoretical shift toward enabling and empowering families (Sloper, 1999; Dunst, 2004; NPC, 2011; Hwenha, 2014). Appendix A outlines seven descriptive studies that exemplify emerging research in affluent countries internationally, and it draws attention to the lack of, and thus need for, similar research in less affluent, developing countries. Nevertheless, the studies identify critical factors and strategies that are utilized by parents who cope and function positively in the face of

ongoing challenges in parenting children with disabilities. Significant findings are discussed in relation to each stage. Finally, factors that currently challenge parents' effective functioning are identified, thereby ascertaining core areas for parent support—particularly for parents from diverse cultural and socio-economic contexts.

Table 1 summarizes the proposed framework as follows: The first column contextualizes parents' help-seeking as a cyclical problem-solving process commencing at pre-intervention when parents' encounter problems in parenting young children with communication difficulties secondary to established disabilities. This process progresses to intervention when parents seek ECCI and communicate problems to professionals, and finally to ongoing intervention when parents implement and evaluate intervention outcomes with professionals (Dunst et al., 1988, 1994a; Björk-Åkesson et al., 1996; Granlund et al., 2005; Bagnato, 2007). The second column integrates the stages and the respective theoretical frameworks of problem orientation and problem definition, within the intervention context outlined. The third column uses the prescribed principles of social problem-solving theory and integrates it in the ECCI context to propose a framework of problem orientation and problem definition to facilitate parents' help-seeking from ECCI (D'Zurilla & Goldfried, 1971; D'Zurilla & Nezu, 1982, 1999, 2010; Sameroff & Fiese, 2000; Granlund et al., 2005; Saloojee et al., 2007; NPC, 2011). The last column identifies factors that currently challenge parents' help-seeking (and by implication parents' problem-solving), thereby identifying specific areas that are needed for parent support.

The theoretical framework of parents' problem orientation is discussed first, followed by the framework of problem definition.

Table 1

*Proposed Framework of Problem Orientation and Problem Definition to Support Parents' Help-seeking in ECCI*

Early Childhood Communication Intervention (ECCI)	Problem-solving framework	Proposed framework of problem orientation and problem definition to facilitate parents' help-seeking in ECCI	Challenges to parents' help-seeking and areas for parent support
<p>1. Pre-Intervention Precursor beliefs and perceptions critical for mobilising parents to seek help in ECCI:</p> <ul style="list-style-type: none"> <li>- Parent aware of problem</li> <li style="text-align: center;">↓</li> <li>- Seeks help from informal social support network (e.g. family)</li> <li style="text-align: center;">↓</li> <li>- Referred to formal social network (e.g. clinic)</li> <li style="text-align: center;">↓</li> <li>- Seeks help from formal social network (e.g. primary health care nurse)</li> <li style="text-align: center;">↓</li> </ul>	<p>1. Problem orientation (five dimensions)</p> <hr/> <ul style="list-style-type: none"> <li>- Problem perception</li> </ul> <hr/> <ul style="list-style-type: none"> <li>- Problem attribution</li> </ul> <hr/> <ul style="list-style-type: none"> <li>- Personal Control</li> </ul>	<ul style="list-style-type: none"> <li>- Perceive problems as a normal part of everyday living.</li> <li>- Recognise that child's communication is a problem.</li> <li>- Believe that help is available and can benefit the child and family, irrespective of the severity of the communication disability.</li> </ul> <hr/> <ul style="list-style-type: none"> <li>- Attribute initial cause of the child's established disability and communication disability to factors external to self that were beyond parents' control.</li> <li>- Understand the transactional relationship between the child and environment, and what this means in understanding global and specific effects of the disability; and maintaining causes of the communication disability</li> </ul> <hr/> <ul style="list-style-type: none"> <li>- Adopt positive expectations towards ECCI, and parents' capacity in accessing intervention.</li> </ul>	<ul style="list-style-type: none"> <li>- National policy and legislation regarding disability</li> <li>- Cultural beliefs and perceptions about disability</li> <li>- Acculturation and enculturation</li> <li>- Cultural influences on help-seeking behaviours (e.g. who seeks help)</li> <li>- Poverty</li> <li>- Support from social network</li> <li>- Perceptions of personal control (outcome expectations and self-efficacy)</li> <li>- Employment constraints on parents' time and energy</li> <li>- Knowledge of health care policies and systems (e.g. eligibility for care, where to begin help-seeking)</li> <li>- Knowledge of typical development of communication to Recognise delay and have realistic expectations (Rossetti, 2001)</li> <li>- Knowledge of transactional regulation between child and</li> </ul>

Early Childhood Communication Intervention (ECCI)	Problem-solving framework	Proposed framework of problem orientation and problem definition to facilitate parents' help-seeking in ECCI	Challenges to parents' help-seeking and areas for parent support
- Referred to SLT	<ul style="list-style-type: none"> <li>• Outcome expectancy</li> <li>• Self-efficacy expectancy</li> </ul>	<ul style="list-style-type: none"> <li>- Believe that ECCI will assist the parent and child in developing a system of communication that is within the capacity of the child's established disability and other risk factors (e.g. general health).</li> <li>- Believe that parent is capable of seeking, acquiring and implementing the intervention required</li> </ul>	<p>environment during development (Sameroff &amp; Fiese, 2000)</p> <ul style="list-style-type: none"> <li>- Knowledge of ECCI and benefits to child, parent and family's positive functioning.</li> <li>- Knowledge of established and/or communication disabilities, contributing to unrealistic expectations regarding intervention outcomes (Rossetti, 2001)</li> </ul>
- Follow up on referral to SLT	- Problem appraisal	- Appraise the communication and established disabilities as challenges that will strengthen parents' well-being.	
	- Commitment of time and effort	<ul style="list-style-type: none"> <li>- Understand that ECCI will take time and effort before positive communication outcomes are noted.</li> <li>- Be prepared to commit time and effort to seek and obtain ECCI for the child, to help develop his/her full potential.</li> <li>- Be realistic in the commitment of time and effort, considering existing work and family demands.</li> </ul>	
<p>2. Intervention</p> <p>Problem definition behaviours critical for mobilising parents' help-seeking in</p>	<p>2. Problem definition (two dimensions)</p> <p>- Organization of information</p>	<p>- Communicate information in an organized 3-step format:</p> <ul style="list-style-type: none"> <li>(i) what is the problem, to whom, and why?</li> <li>(ii) What is the help needed, by whom and why?</li> <li>(iii) what is currently preventing the parent from helping the child?</li> </ul>	<ul style="list-style-type: none"> <li>- Confidence in communicating with the SLT (influenced by education, culture, language, socio-economic status, knowledge and skill in communicating problems and needs)</li> <li>- Beliefs about the role of parents and professionals during help-</li> </ul>

Early Childhood Communication Intervention (ECCI)	Problem-solving framework	Proposed framework of problem orientation and problem definition to facilitate parents' help-seeking in ECCI	Challenges to parents' help-seeking and areas for parent support
<p>ECCI:</p> <ul style="list-style-type: none"> <li>- Participate in collaborative problem-solving with SLT</li> </ul> <p style="text-align: center;">↓</p> <ul style="list-style-type: none"> <li>- Communicate problem and needs to SLT</li> </ul> <p>3. On-going intervention</p>	<p>Relevance of information</p>	<ul style="list-style-type: none"> <li>- Provide information that is:               <ul style="list-style-type: none"> <li>• <b>Specific</b> to communication and other associated problems (i.e. body structure and functioning, activities and participation)</li> <li>• <b>Concrete</b> – using many examples from the home and other relevant contexts</li> <li>• <b>Comprehensive</b> – begin from the onset of the problem until the present time.</li> </ul> </li> <li>- Implement ECCI programme with child in the home context</li> <li>- Evaluate implementation in terms of what works and what does not</li> <li>- Communicate successes and problems to SLT at follow-up interventions</li> <li>- Continue collaborative problem-solving during ECCI</li> </ul>	<p>seeking.</p> <ul style="list-style-type: none"> <li>- Beliefs about ECCI (benefit to parent and child)</li> <li>- Parents' mental health (depression, anxiety, denial)</li> <li>- Family's decision-making and who provides information to professional during help-seeking</li> </ul> <p>- Ongoing support in specific areas, as required.</p>

### **2.3.1 Problem orientation: Facilitating parents' constructive approach to help-seeking**

Problem orientation is the motivational component of social problem-solving that mediates individuals' approach to or avoidance of problem-solving activities (D'Zurilla & Nezu, 1982, 1999, 2010). The component is crucial in prompting individuals to initiate and sustain problem-solving activities. As stated, an attentional set enables recognition of problems in daily life, and a cognitive-emotional schema set mediates individuals' typical approach to thinking and feeling about two issues: (i) Problems in general, and (ii) the individual's problem-solving ability (D'Zurilla & Nezu, 1999, 2010). The cognitive-emotional schema set is derived from individuals' beliefs and appraisals about problems encountered (D'Zurilla & Nezu, 1999, 2010). A set is an "inferred predisposition that influences a client to behave in a certain manner, which can be either facilitative or disruptive, depending on whether it moves the client toward or away from an effective ... solution" (Heppner, 1978, p. 367). Facilitative or positive problem orientations are constructive and promote positive emotions and approach tendencies, engagement in problem-solving behaviour, attention to productive problem-solving activities, increased effort, persistence and tolerance for frustration and uncertainty (D'Zurilla & Nezu, 1999, 2010). Disruptive or negative problem orientations are dysfunctional and generate negative emotions and avoidance tendencies, increased worrying which is destructive and reduced effort, persistence and tolerance for frustration and uncertainty (D'Zurilla & Nezu, 1999, 2010). Knowledge of the problem orientation process and of factors that influence positive and negative orientations are important, particularly the latter, in order to develop interventions that enhance individuals' recognition of and/or constructive approach to problems to be provided.

The theory of social problem-solving conceptualises problem orientation as five major dimensions that constitute the problem orientation construct, to facilitate assessment and support (D'Zurilla & Nezu, 1999, 2010). The dimensions are: (i) problem perception; (ii) problem attribution, (iii) problem appraisal, (iv) personal control and (v) time and effort commitment (D'Zurilla & Nezu, 1999, 2010). Problem perception refers to the attentional set in recognising problems, while the remaining four dimensions relate to the relatively stable cognitive-emotional schema set that describes individuals' beliefs and appraisals that predispose a typical approach to thinking about problems and the capacity to solve problems (D'Zurilla & Nezu, 1999, 2010). The construct of problem orientation is particularly relevant for parents of young children with

communication disabilities secondary to established disabilities, to implement the roles of consumer and decision-maker when accessing support (Granlund et al., 2005). The construct describes parents' motivation with respect to: initiating help-seeking and access to ECCI; participating actively during collaborative problem-solving with professionals; committing time and effort to implement intervention; and sustaining engagement despite the frustrations and uncertainties associated with parenting children with disabilities (D'Zurilla & Nezu, 1999, 2010; Rossetti, 2001; McConkey, 1995; Saloojee et al., 2007). The construct considers critical issues that are significant in optimizing parents' resilience (Walsh, 2003). Parent motivation to access and sustain ECCI is shaped significantly by their beliefs and appraisals regarding children's communication and established disabilities, which in turn influences their thinking and feelings about the disabilities and their capacity for seeking help (D'Zurilla & Nezu, 2010; McConkey, 1995). The latter are affected by parents' experiences with people with disabilities and are important in facilitating their coping with and adaptation to parenting children with disabilities (McConkey, 1995; Rossetti, 2001; D'Zurilla & Nezu, 1999; Saloojee et al., 2007). Despite its critical relevance for parents as consumers and decision-makers in achieving effective and sustainable ECCI outcomes, parent motivation toward seeking help, as conceptualised in the problem orientation construct, receives fragmented attention as a critical mediator of collaborative problem-solving in ECI and ECCI.

A broad review of descriptive and intervention studies in the ECI literature reveals that parent motivation toward seeking help is explored minimally from a problem-solving perspective, and hence, the term 'problem orientation' is unfamiliar. While models of collaborative problem-solving in ECI are derived from the psychological theory of problem-solving, differences are noted in the extent to which problem orientation is included as a critical part of the assessment and intervention process, reflecting varied recognition of its significance for positive ECI outcomes (Coufal, 1993; Björk-Åkesson et al., 1996; Dunst et al, 1988, 1994a; Heppner & Petersen, 1978; D'Zurilla & Nezu, 1982). For example, problem orientation is not included in the model of collaborative problem-solving proposed by Björk-Åkesson and Granlund (Björk-Åkesson et al., 1996; Granlund et al., 2005). Coufal (1993) introduced the construct as proposed in social problem-solving theory, but does not explore it fully for ECI.

The majority of collaborative assessment and intervention models, exemplified by Dunst et al. (1988, 1994a); Rossetti (2001) and Dunst (2004), consider the concept broadly in relation to parents' coping, adaptation and positive functioning. The theoretical association of parents' coping and functioning with their problem-solving capacity, however, is not made explicit. The ECI literature on parent coping, adaptation and positive functioning in developed and developing countries is currently based largely on descriptive compared to intervention research, with a significant need for both types of research in developing countries such as South Africa. The research is shaped by widely used psychological theories, such as Lazarus & Folkman (1984); Turnbull, Patterson, Behr, Murphy, Marquis and Blue-Banning (1993); Taylor (1983); and theories that emphasise positive functioning, such as Antonovsky (1993); Elliott, Kurylo & Rivera (2002) and others included in Snyder & Lopez (2002). While the theories reflect a basic level of shared understanding regarding effective functioning, broader differences in conceptualisation and operationalisation contribute to the fragmentation evident in understanding and supporting parents. Table 2 briefly describes a sample of 13 parent intervention studies to facilitate parents' coping and adaptive functioning in parenting children with disabilities. The studies typify the nature of support provided in ECI in developed and developing countries. A detailed summary of the studies is presented in Appendix B. A critical evaluation of the studies' intervention focus is provided in Table 2, highlighting the parenting role and coping variable targeted.

Table 2

*Intervention Focus in Studies Supporting Parents' Coping and Functioning in Parenting Children with Disabilities*

Author	Aim & Method	Results	Critical evaluation highlighting intervention's focus on parenting role and coping variable	
			Parenting role	Coping Variable
Moxley-Haegert & Serbin (1983)	To compare the effectiveness of three treatment conditions [i.e. developmental education (DE), child management education (CME) & no education] on 39 parents' motivation to participate in home programmes, using an experimental and control group design.	DE parents showed improved ability to discriminate and report on child's progress. Gains continued at post-intervention and follow-up. Concluded that parent recognition of small levels of developmental progress reinforced and motivated parents to increase participation in home programmes.	Caregiver  Trainer  Decision-maker	Personal control  (via knowledge of child's development)
Baker, Landen & Kashima (1991)	To establish if intervention had a broader impact on 49 parents/families of children with mental retardation, Down Syndrome and autism, using a pre-post intervention design. To also establish parent and family characteristics that predicted successful outcomes	Intervention showed small but significant decreases in parent reports of depression, parent/family problems, family stress and dissatisfaction with family adaptation and cohesion.  Significant predictors of drop-outs: single parents, low marital adjustment, low income, low pre-training teaching skills, high family stress, low adaptation/ cohesion. Low	Caregiver  Trainer	Personal control  (via engagement in child intervention)

Author	Aim & Method	Results	Critical evaluation highlighting intervention's focus on parenting role and coping variable	
			Parenting role	Coping Variable
		follow-through families were less positive about family, showed poorer marital adjustment and more dissatisfaction with family adaptation.		
<b>Davis &amp; Rushton (1991)</b>	To describe an evaluation of a home-based, family-focused parent-advisor counselling scheme, providing support to English-speaking (n=52) and Bangladeshi families (n=28) of children with intellectual or multiple disabilities, in separate groups. Each group was randomly assigned to a control and intervention group.	Counselling intervention benefitted both groups, but the Bangladeshi mothers (who were poorer than the English-speaking group) derived greater benefits with respect to: mothers' self-efficacy, confidence, positive perceptions of the child and family, decreased stress, and developmental progress and behaviour of the child (although intervention did not target the latter).	Caregiver  Decision-maker	Personal control  Self-efficacy  (via parent counselling)
<b>Bristol, Gallagher &amp; Holt (1993)</b>	To assess the impact of psycho-educational intervention on depressive symptoms in 28 mothers of children with autism and severe communication disabilities, using an experimental and control group	Experimental group mothers showed gradual increases in feelings of control, resulting in gradual improvement in depression over time. Findings imply that depression is a modifiable adjustment reaction to the stress of caring for children with	Caregiver	Personal control  Problem appraisal

Author	Aim & Method	Results	Critical evaluation highlighting intervention's focus on parenting role and coping variable	
			Parenting role	Coping Variable
	design.	chronic disability.		(via parent counselling)
<b>Pelchat, Bisson, Perreault &amp; Bouchard (1999)</b>	To assess longitudinal effects of an early intervention programme on adaptation of 74 parents of children with Down Syndrome (DS) and cleft lip and palate (CLP), using an experimental and control group design.	Intervention facilitated positive outcomes as parents felt less threatened; more confident to receive help from others; less emotional distress, anxiety and depression; perceived more emotional support from spouse, and felt greater confidence in using own resources to cope. Mothers more inclined to see the situation as a challenge.	Caregiver  Consumer	Problem appraisal  Self -efficacy  (via parent counselling)
<b>Morrison, Bromfield &amp; Cameron (2003)</b>	To describe a therapeutic model for supporting families of children with chronic illness or disability	Description outlines types of interventions (e.g. counselling); principles (e.g. family-centred, non-illness specific); and methods (e.g. empowerment, coping, resilience, reframing).	Caregiver	Problem appraisal  Personal control  (via parent counselling)

Author	Aim & Method	Results	Critical evaluation highlighting intervention's focus on parenting role and coping variable	
			Parenting role	Coping Variable
<b>Barnett et al., (2003)</b>	To describe a parent group intervention to promote adaptation to raising a child with special needs due to chronic medical conditions or disability	Intervention is based on a four-process theoretical framework of parent support, namely, social, emotional, cognitive and behavioural. Mechanisms of change and parents' readiness to change are also considered. The intervention requires empirical evaluation.	Caregiver	Problem appraisal  Personal control  (via parent counselling)
<b>Bolton (2004)</b>  <b>South Africa</b>	To describe a parent-child intervention to assist families in coping with young children at risk or diagnosed with communication difficulties	Child outcomes included increased communication, listening, concentration, and interest in books and play. Caregiver outcomes included better communication and a more positive relationship with the child. Specific mechanisms that contributed to positive parent outcomes are not explored.	Caregiver  Trainer	Personal control  (via child-focused communication intervention)
<b>Margalit &amp; Kleitman (2006)</b>	To examine factors that predict stress in 70 mothers of children with developmental disabilities (0-3 years) pre-and-post intervention, and to identify	At pre-intervention mothers with a higher sense of coherence had lower stress. Post-intervention predictors were mothers' coping strategies (individual perceptions), family cohesion, and satisfaction with	Caregiver	Problem appraisal  Self-efficacy

Author	Aim & Method	Results	Critical evaluation highlighting intervention's focus on parenting role and coping variable	
			Parenting role	Coping Variable
	mothers who were resilient.	intervention, had lower stress.		(via parent counselling)
<b>Tonge, Brereton, Kiomall, Mackinnon, King &amp; Rinehart (2006)</b>	To assess the impact of a parent education and behaviour management (PEBM) intervention on the mental health and adjustment of parents of children with autism (2.5-5 years). A randomized three group comparison design included parent education and counselling (PEC), and early childhood services.	Greater than 50% of the parents had serious mental health problems at pre-testing. The PEBM and PEC interventions had similar positive effects especially with parents who had pre-existing mental health problems.	Caregiver	Problem appraisal  Personal Control  (via parent counselling)
<b>Herbst &amp; Maree (2006)</b>  <b>South Africa</b>	To describe a two phase approach to develop an empowerment programme for parents in the NICU: (i) focus group with parents (n=12) to identify needs, and (ii) a workshop with neonatal nurses (n=20) to develop guidelines for parent empowerment, using	Parents identified needs regarding personal control (information, informed decision-making, participation in child care), emotions and coping (causal-attribution/self-blame/denial), communication with professionals, developing a therapeutic NICU environment and discharge. Nurses developed supportive guidelines to	Caregiver  Consumer	Personal control  Problem attribution  Problem

Author	Aim & Method	Results	Critical evaluation highlighting intervention's focus on parenting role and coping variable	
			Parenting role	Coping Variable
	findings from phase (i).	empower parents.	Decision-maker	perception
<b>Barlow, Coren &amp; Steward-Brown (2009)</b>	To evaluate the effectiveness of group-based parenting programmes in improving maternal psychosocial health (e.g. anxiety, depression, self-esteem). Used randomized control trials with 26 mothers of children from birth to adolescence with behaviour problems or disabilities (e.g. ADHD, intellectual disabilities, Down Syndrome etc.).	Improvement in depression, anxiety/stress, self-esteem, marital relationship – but not social support in treatment group. Concluded that parenting programmes are effective in improving maternal psychosocial health in the short-term. Long-term effects are lacking, and need further research.	Caregiver	Problem appraisal  Personal control  (via parent counselling)
<b>Black, McConkey, Roberts &amp; Ferguson (2010)</b>	To describe a person-centred support service for families caring for children with severe learning disabilities in rural and urban areas, and a three year formative evaluation of the programme.	Assisted parents to clarify individual support needs, and involved children in ordinary community activities with non-disabled children (e.g. outdoor games). Support was rated highly by parents, children, volunteers and staff.	Caregiver  Consumer  Decision-maker	Problem appraisal  Personal control  (via parent counselling & child focused intervention)

The review reflects the lack of a systematic approach to supporting parents' effective functioning in the four parenting roles of caregiver, consumer, decision-maker and trainer, as discussed in Section 1.2 (Granlund et al., 2005). Limited attention is given to the role of consumer and decision-maker, as operationalised in Figure 1, for help-seeking in ECCI. In addition, while the interventions focus largely on promoting two coping variables, namely, personal control, followed by problem appraisal, reference to a unifying theoretical framework linking the two variables (and others noted) for effective functioning, is absent. The construct of problem orientation synthesizes research on the different coping variables through its five-dimensional framework. In so doing, the construct provides an integrated framework to conceptualise, assess and support parents' coping and functioning in the four parenting roles, from a social competence perspective, (D'Zurilla & Nezu, 1999, 2010). This study proposes using the framework to understand and support parents' help-seeking, specifically in the roles of consumer and decision-maker.

The theory of social problem-solving emphasises two processes that contribute to the outcomes of positive or negative orientation. Firstly, the dimension of problem perception in recognising problems and the resources to alleviate problems, and *initiating* the problem-solving process. Secondly, the cognitive processing in each of the remaining four dimensions that comprise the general cognitive-emotional schema set. Besides speculating that "problem attribution is likely to influence problem appraisal" (D'Zurilla & Nezu, 1999, p. 20), the theory does not elaborate on the nature of the relationship among the four dimensions of the cognitive-emotional schema set to explain the mechanisms involved in achieving positive or negative orientations. The conceptualisation of problem orientation as a multidimensional construct, however, would assist in clarifying the nature of these relationships and thereby, the mechanisms for change. As discussed in management research, the theoretical basis of multidimensional constructs reflected three important aspects: (i) the constructs contain more than one dimension, (ii) the dimensions are interrelated, and (iii) the nature of the relationship between the dimensions and the overall construct is specified in order to draw relevant conclusions about the composite construct (Law & Wong, 1999; Wong & Law, 2008). With respect to the third aspect, two ways of viewing the relationship between individual dimensions and the composite construct are specified, and each view contributes to a different outcome: (i) the *composite view* assumes

that the dimensions are components of the multidimensional construct, therefore the composite construct is the outcome of the dimensions; and (ii) the *factor view* assumes that the dimensions are different manifestations of the multidimensional construct, and therefore the composite construct is the common or latent construct (Law and Wong, 1999). Although the problem orientation construct appears to characterise a multidimensional construct in structure, the theory of social problem-solving does not explicitly define it as such, and the interrelationships among the dimensions of the cognitive-emotional schema set especially, appears underspecified. Therefore, from a problem orientation perspective it is not possible to identify core dimensions that are critical in mediating positive orientation outcomes. Such knowledge would aid support programmes to prioritize specific dimensions to facilitate positive orientations, and thereby positive functioning.

In contrast, theories of coping, adaptation and positive functioning foreground the critical roles of the three dimensions of problem attribution, personal control and problem appraisal (Taylor, 1983; Lazarus & Folkman, 1984; Antonovsky, 1993; & Elliott et al., 2002). Lazarus & Folkman (1984), Antonovsky (1993) and Elliott et al. (2002) go a step further and conceptualise problem appraisal as central and, by implication, the dimensions of problem attribution and personal control may be perceived as mediators of problem appraisal. To illustrate this point, a brief overview of the theories by Taylor (1983), Antonovsky (1993) and Elliott et al. (2002) is provided, and issues specific to the three dimensions are explained.

Taylor's (1983) theory of cognitive adaptation foregrounds two dimensions of problem orientation, namely problem attribution and personal control. The theory identifies three aspects that mediate adaptation to threatening events: (i) attributing a cause for the event; (ii) establishing a sense of mastery or control over the event in particular and over life more broadly; and (iii) enhancing one's self esteem. In contrast, Antonovsky's (1993) theory of successful coping focuses on individuals' sense of coherence (SOC) as a key factor which, applied to this study, refers to parents' "integrated way of looking at the world" they live in (Antonovsky, 1993, p. 117). Three prerequisites for successful coping with any problem are identified and these correspond to three dimensions of problem orientation, namely comprehensibility (i.e., problem attribution), manageability (i.e., personal control), and meaningfulness (i.e., problem appraisal) (Antonovsky, 1993). The implication of the above for this study is that parents cope

and adapt positively when they believe they understand the problem/s related to parenting their child with a disability (e.g. in terms of what the disability is, and what caused it). They believe that they have the resources (or access to resources) they need to manage or alleviate the problem/s, and they are motivated and wish to cope with the problem/s in order to achieve desired family values. Antonovsky (1993) identifies meaningfulness as the critical motivational component that is central to positive functioning. The latter component relates to the dimension of problem appraisal in social problem-solving theory, which is discussed later. Finally, Elliot et al. (2002) proposed an integrated, dynamic model of adjustment with appraisal as the central component that is influenced by individuals' characteristics and immediate social and interpersonal environment - both influencing psychological well-being and physical health. The model views adaptation as a dynamic, developmental process that strengthens the impetus for parent support. Although the theory relates specifically to positive growth following acquired physical disability in adults, the central tenets are relevant for supporting parents of children with disabilities as well. Thus, theories in the field of coping, adaptation and positive functioning emphasise the central role of problem attribution in facilitating problem appraisal and, thereby, positive orientations to problems. In this context, problem attribution and personal control appear to play important mediating roles.

The construct of problem orientation is discussed next, according to the five dimensions proposed in the psychological literature (D'Zurilla & Nezu, 1999, 2010). However, the dimensions are not discussed in the sequence proposed in social problem-solving theory and illustrated in Figure 1 and Table 1. Instead, the centrality of problem appraisal in mediating individuals' overall orientations to problems is recognised, in line with the study's conceptualisation of help-seeking as a problem-focused coping strategy (discussed in Section 2.3.1). Problem appraisal is therefore discussed after considering the dimensions of problem attribution, personal control, and time and effort. Key principles that facilitate effective social problem-solving are identified from the psychological perspective, and applied critically to ECCI in order to develop a framework of problem orientation that facilitates parents' help-seeking. Factors that currently challenge parents' positive orientations and that contribute to dissatisfaction in accessing interventions that meet their needs, are identified. The critical significance of the construct is demonstrated at two levels: (i) in mediating parents' help-seeking

and access to intervention, and (ii) in providing a systematic approach to assess and identify core issues for parent support.

### **2.3.1.1 Problem perception**

Problem perception is an important prerequisite for effective problem-solving and refers to the individual's readiness to recognise problems when they occur, instead of ignoring or denying them (D'Zurilla & Nezu, 1999, 2010). Problem recognition and identification initiates the remaining four problem orientation schemas, and creates the context for problem-solving proper (i.e., the four goal-directed tasks reflected in Figure 1, which are important for successful problem resolution). Problems experienced in daily living are generally ambiguous, containing relevant and irrelevant information that need to be clarified to clearly define what the real problem is (D'Zurilla & Nezu, 1999, 2010). Labels that are used to identify a problem may affect the problem-solving process due to the meanings and significance attached, since these emanate from individual's beliefs, values and prior learning (D'Zurilla, 1986). For effective problem-solving activities to ensue, there must be an attitude of acceptance that problems are a normal and inevitable part of life, and that it is possible to cope with the uncertainties prevalent in problematic situations by engaging in problem-solving (D'Zurilla & Nezu, 1999, 2010).

In the context of parents' seeking help in ECCI as outlined in Table 1, the first critical step is parents' perceptions of problems in parenting young children with moderate to severe communication disabilities secondary to established disabilities. As currently understood in ECI and supported by social problem-solving theory (Dunst et al., 1988; Dunst & Deal, 1994a; Björk-Åkesson et al., 1996; D'Zurilla & Nezu, 1999, 2010), problem perception precedes parents' initiation of help-seeking and describes parents' capacity as caregivers to firstly recognise the following: (i) that the child's limited or absent communication skills is a problem that contributes to parenting challenges experienced, in addition to the established disability, (e.g. child cries but unlike other children of similar age or disability, she/he is unable to indicate cause); (ii) that the child's communication is a valued developmental skill that is important in developing and maintaining the family's daily routine and in promoting children's social and academic lives (Björk-Åkesson et al., 1996; Rossetti, 2001); and (iii) that other co-occurring difficulties, such as poverty, add to parenting problems. Secondly, problem perception describes parents' capacity to

subsequently identify resources that can alleviate these problems (e.g. ECCI services). Both issues involve parents' recognition of problems and identification of needs that will resolve problems, and although considered in ECI, a common systematic approach to assess and support this first step is lacking (Dunst et al., 1988; Dunst & Deal, 1994b; Björk-Åkesson et al., 1996).

The construct of problem orientation includes further perceptions that are considered inadequately in the ECI parent support literature. It includes parents' understanding that: the problems associated with children's communication and established disabilities are similar to any other problematic situation that families confront in their normal daily lives; they can cope with demands that exceed their capacity by seeking help from informal and formal social networks; and that there are formal social networks such as ECCI that can help irrespective of the severity of problems experienced (D'Zurilla & Nezu, 2010; Beresford, 1994; Sloper, 1999). Therefore, in consolidating the principles of problem orientation as proposed in the theory of social problem-solving and current ECI literature (D'Zurilla, 1986; D'Zurilla & Nezu, 1999, 2010; Dunst et al., 1988, 1994a; Björk-Åkesson et al., 1996), it is concluded that parent motivation to initiate and sustain help-seeking in ECCI is facilitated by parents' constructive perceptions of problems and needs in general; the value placed on communication skills; their capacity to recognise problems and identify needs in relation to the child's communication and other competing problems; and their recognition of ECCI as a resource for support.

Descriptive studies in ECI that profile parents who cope and function positively in parenting children with disabilities highlighted the significance of parents' perceptions of problems in two areas, namely (i) facilitating decision-making and problem-solving and (ii) contributing to adaptive coping and transformational functioning (Appendix A). The studies identified perceptions that were critical in motivating parents to initiate and sustain help-seeking as having constructive, positive perceptions and an optimistic outlook regarding the child's disability and the parents' circumstances in general, accepting the situation quickly and moving forward to identify needs and utilize available resources to access help, willingness to accept help, persisting by using trial and error until an appropriate solution is found, and perceiving the family as 'normal', like any other family managing a challenging event (Scorgie, Wilgosh, McDonald, 1996, 1999; Scorgie & Sobsey, 2000; Larson, 1998; Grant & Whittell, 2000; Taanila, Syrjälä, Kokkonen & Järvelin, 2002; & Maul & Singer, 2009). While the parents in these studies

were from different race and economic backgrounds, they accessed ECI from the more affluent countries internationally. Consequently, there is a need to establish whether parents from less affluent countries function similarly in light of additional constraints that are discussed next (Kisanji, 1995; McConkey, 2005; Hwenha, 2014).

The ECI literature reveals that there are many factors that challenge parents' capacity to perceive problems, identify needs, and seek and sustain help as proposed for their children with communication and established disabilities. Early identification of such factors and the implementation of relevant parent support are imperative in facilitating parents' help-seeking capacities, particularly for parents living under adverse socio-economic conditions in less affluent countries like South Africa. Table 1 categorizes factors at the macro-system, meso-system and micro-system levels (Bronfenbrenner, 1986; Dunst, Trivette & LaPointe, 1994; Sameroff & Fiese, 2000). It is the combined interactions across the five dimensions of problem orientation and the stage of problem definition that ultimately mediate parents' positive or negative orientations toward seeking help. Relevant macro-system factors include countries' disability policies and implementation, and the populations' diverse culture, language, and economic backgrounds; meso-system factors relate to parents' interaction with formal support from ECI professionals, whilst micro-system factors focus on the parent with respect to culture, education and literacy, employment and income, and health; and the implications of these factors for their knowledge of, perceptions of, and skills in disability and management, and personal control (self-efficacy and outcome expectations). The factors are introduced and discussed as they apply for each stage and dimension of social problem-solving. Significant factors and issues for the dimension of problem perception are considered.

At the level of the macro-system, countries' disability legislation and policies provide the mandate and mechanisms for caring for young children with disabilities (Kisanji, 1995; Storbeck & Moodley, 2011). It is an important factor that influences parents' perceptions of problems and needs regarding disability and their motivation to seek help, provided that they are aware of and knowledgeable about it. At an international level, while legislation and policies are generally more favourable in affluent countries (e.g. in North America, Britain, Australia and Europe) compared to less affluent and developing countries (e.g. in South America and Africa), issues at the level of implementation continue to plague both contexts (McConkey, 2005; World Health

Organization, 2011). The situation for less affluent countries such as South Africa though, is far more challenging (Storbeck & Moodley, 2011; Samuels et al., 2012). Two important reviews of the health and health system of South Africa contextualize the challenges confronting the public health system in relation to the country's historical colonial and apartheid past pre-1994, to the current post-apartheid era, namely, Coovadia, Jewkes, Barron, Saunders, and McIntyre (2009), and Mayosi, Lawn, van Niekerk, Bradshaw, Karim and Coovadia (2012). The reviews outline challenges specific to racial inequality, poverty and unemployment, fragmentation and the quality of service delivery, and the quadruple burden of diseases (i.e. HIV and tuberculosis; maternal, neonatal and child health; non-communicable diseases and mental health; and violence and injury). The challenges have direct relevance for disability issues and contributed to the establishment of the Department of Women, Children and Persons with Disability in government in 2009. Specific to ECI in South Africa, the current South African legislative framework provides a progressive, strong foundation for the support of children with disabilities through policies such as the White Paper on the Integrated National Disability Strategy (Office of the Deputy President, 1997), White Paper 6 on Special Needs Education (Department of Education, 2001), and the National Integrated Plan for Early Childhood Development (ECD) in South Africa 2005-2010 (UNICEF, 2005). However, the policies were initiated separately in three government departments, namely, health, social welfare and education. Consequently the approach is fragmented, and inadequate attention is given to issues that are specific to supporting children with disabilities and their families, such as transport (Storbeck & Moodley, 2011; Samuels et al., 2012). While the National Integrated Plan for Early Childhood Development in South Africa 2005-2010 (UNICEF, 2005) attempted to provide a coordinated approach to ECD broadly, it focused on a restricted age range and type of disability (i.e., children 0-4 years who have physical disabilities). The policies promote primary health care, community-based rehabilitation and home-based care, but implementation in rural and urban contexts is challenging due to limitations in health and education infrastructure, finance allocated for disability and the number and skill of human resources (Fair & Louw, 1999; McConkey, 2005; Emmet, 2005; NPC, 2011; Storbeck & Moodley, 2011; Coovadia et al. 2009; Mayosi et al., 2012; Samuels et al., 2012; Hwenha, 2014; Moonsamy & Kathard, 2015). The implications for parents of children with disabilities are twofold with respect to perceiving problems and needs,

and initiating and sustaining help-seeking: (i) limited awareness of legislation and policies, and consequently their right to appropriate treatment, and (ii) poor access to quality support programmes from trained health and education personnel at primary health care settings.

Diversity in the populations' culture and economic profile are further factors at the macro-system level that challenge parents' perceptions of problems, needs and motivation toward seeking help (Kisanji, 1995; McConkey, 1995; Rossetti, 2001; Alant, 2007; Neely-Barnes & Dia, 2008; Samuels et al., 2012; Hwenha, 2014; Kathard & Moonsamy, 2015). These factors are discussed from the perspective of parents' help-seeking at the meso- and micro-system levels. Culture refers to a framework of shared beliefs, values and practices that are learned and transmitted from one generation to the next in a defined group of people and includes religion, health and family habits (Sturm & Gahagan, 1999). The family's cultural context plays a critical role in influencing parents' daily functioning in parenting children with disabilities, thus influencing knowledge and decision-making about what are perceived as problems and needs and the help-seeking process. For example, cross-cultural literature in ECI foregrounds two significant issues in many African and Asian countries: (i) the control of family decision-making by men, thus emphasising gender issues; and (ii) the priority placed on accessing traditional healers as an initial or concurrent solution with western medicine (Kisanji, 1995; McConkey, 1995; Sturm & Gahagan, 1999; Harry, 2002; NPC, 2011; Mayosi et al., 2012). The literature clearly foregrounds parents' beliefs and values regarding disability and management as central influences on help-seeking (McConkey, 1995; Kisanji, 1995; Harry, 2002; Saloojee et al., 2007; Neely-Barnes & Dia, 2008; Kathard & Moonsamy, 2015). Parents' beliefs are personally formed or culturally shared notions about reality that operate at a tacit level during appraisal to determine what is fact and meaningful (Lazarus & Folkman, 1984). Commitment or values, on the other hand, are parents' individual characteristics that express what is important and meaningful to parents, it underlies their choices to maintain valued ideals; it has an important motivational quality (Lazarus & Folkman, 1984). International and national cross-cultural literature strongly emphasise the varying effects of three factors in diversifying beliefs and values within specific cultural groups and within individual families, that is, acculturation, parents' education, and economic status (McConkey, 1995; Zinkin, 1995; Sturm & Gahagan, 1999; Harry, 2002; Beuster & Schwär, 2005; Fair & Louw, 1999; NPC, 2011;

Hwenha, 2014; Kathard & Moonsamy, 2015). These factors affect other co-occurring factors such as families' social support, geographic location, immigrant and generational status, and parents' health (Sturm & Gahagan, 1999; Harry, 2002; Zhang & Bennet, 2001; McConkey, 1995, 2005; Kisanji, 1995; Hwenha, 2014). Thus, the literature cautions against viewing families through expectations derived from cultural stereotypes in light of the co-occurrence and interaction of macro-, meso- and micro-system factors (Sturm & Gahagan, 1999; Harry, 2002; Neely-Barnes & Dia, 2008; Moonsamy & Kathard, 2015).

Parents' beliefs and values regarding disability, early identification and management and their role in accessing and participating in intervention are thus prominent in mediating parents' motivation towards seeking help (McConkey, 1995; Sturm & Gahagan, 1999; Harry, 2002). With respect to parents' perception of communication and established disabilities in young children, early identification is strongly related to: (i) the type and severity of the disabilities; and (ii) parents' values and expectations regarding typical and atypical child development, which are largely derived from cultural norms within specific communities (Kisanji, 1995; Rossetti, 2001; Harry, 2002). Although severe and easily recognised disabilities (e.g. Down Syndrome) are likely to be identified early, parents' often delay or don't access ECI services due to communities' negative beliefs/attitudes towards disability, and/or poverty (Samuels et al., 2012). This is discussed further in section 2.3.1.2 and illustrated in case studies described by Kisanji (1995).

Atypical behaviours in developmental areas that are highly valued by the community are more likely to be identified and managed early compared to those that are not, as illustrated in the following studies. Sturm and Gahagan (1999) highlighted differences in parents' identification of feeding problems in young children which influenced help-seeking practices. The study found, for example, that Puerto Rican mothers expected independence at later ages compared to African American mothers. With regard to early identification of communication disabilities in young children, three issues that influenced parents' early recognition and the decision to seek help from ECCI were parent's existing knowledge about communication development, its significance for social and academic competence, and the benefits of ECCI services (Rossetti, 2001; Saloojee et al., 2007). In Southern Africa, Brodin and Molosiwa (2000) conducted interviews with 47 parents in Botswana, to identify their needs in relation to children

with mental retardation. Many parents perceived the need for financial support, but very few identified support from SLTs (as well as from occupational therapists and physiotherapists). The findings indicated lack of familiarity with the roles of these professionals and emphasised that financial resources were a greater priority for parents at the time. The latter priority and the country's greater acceptance of deviance in general, accounted for the lack of parental stress regarding the child's diagnosis (Brodin & Molosiwa, 2000). Early recognition of communication disabilities and the need for ECCI support is therefore unlikely, in view of competing needs, definition and acceptance of disability. In addition, parents' knowledge of the services provided by specific ECI professionals also influence decisions to access support. The findings are relevant for many families living in sub-Saharan African countries, including South Africa (Hwenha, 2014). The discriminatory legacy of apartheid in South Africa played a crucial role in influencing the help-seeking behaviours of Black South Africans in accessing ECI and ECCI due to limited knowledge about such services. Historically, SLTs and audiologists were mainly white English and Afrikaans speaking females who served the minority white population, thereby leaving the majority Black population unaware of specialised services, and thus under-served (Pillay, Kathard & Samuel, 1997; Kathard & Moonsamy, 2015; Kathard & Pillay, 2013; Pillay & Kathard, 2015). The training of therapists from the majority Black population has increased gradually in the post-apartheid era contributing to increased services at public institutions (e.g. community clinics and district hospitals), however, the majority Black population remains uninformed and under-served (Kathard & Moodley, 2015).

For parents of children with disabilities in less affluent countries issues of poverty, literacy and education affected each other and strongly influenced parenting and the nature of problems and needs that parents identified (McConachie & Zinkin, 1995; Dunst et al., 1988; 1994a; Dunst, 2004; Kathard & Pillay, 2013; Thrush & Hyder, 2014; Lygnegård, Donohue, Bornman, Granlund & Huus, 2013; Samuels et al., 2012; Moonsamy & Kathard, 2015). The lack of basic resources and limited access to social support added to an already stressful life experience. According to Alant and Lloyd (2005), when basic survival needs are not met, parents will perceive these needs as more urgent than the need to improve the child's severe communication or other problems associated with established disabilities. The argument is derived from Maslow's theory of motivation, which places physiological needs (e.g. food and

shelter) higher than needs such as belonging, esteem and self actualization (Maslow, 1954). Parent motivation to attend ECCI is unlikely to be high if intervention does not address basic needs as well (Lygnegård et al., 2013; Samuels et al., 2012). Baxter & Kahn (1999) investigated the needs, supports and stresses of American urban families living in poverty at two points during intervention—at the first consultation and approximately 12 months later at the second consultation, to determine whether participation in intervention made any difference. Many of the needs that families identified during the first consultation dealt with important survival issues such as food, shelter, transport, medical information, limited personal time and feelings of stress. The findings indicated no significant difference between scores from the first to the second consultation, reflecting the limited focus of intervention on parents' basic needs. The study highlighted the need for broad-based family support and noted that families would engage to meet their basic needs on their own if not provided, which would have a negative impact on intervention outcomes. Despite wide endorsement of the need for broad-based family support and notable advances made in developed and developing countries, the current situation for families, specifically in less affluent countries, remains a major challenge to date (Coufal, 1993; Kisanji, 1995; McConkey, 1995; Dunst et al., 1988; 1994a; Dunst, 2004; Brodin & Molosiwa, 2000; Sloper, 1999; Alant & Lloyd, 2005; Saloojee et al., 2007; NPC, 2011; Mayosi et al., 2012; Samuels et al., 2012; Lygnegård et al., 2013; Thrush & Hyder, 2014; Hwenha, 2014).

In South Africa, approximately 94% of poor people are Black South Africans (Statistics South Africa, 2014) and the majority of black children with disabilities continue to live in extreme poverty, under in-hospital conditions with poor access to health care facilities and ECI (Saloojee et al., 2007; NPC, 2011; DSD, DWCPD & UNICEF, 2012; Samuels et al., 2012; Hwenha, 2014). Oldewage-Theron & Slabbert (2010) investigated the depth of poverty in an urban informal settlement in South Africa and found that 67% of the 429 randomly selected households lived in poverty with a mean monthly income of R612.50, and only one person in 87% of the households was employed. The majority of the households were female-headed (56%), and 10% were headed by grandparents. Minimal shifts in poverty trends were noted in the recent poverty analysis report by Statistics South Africa (Statistics South Africa, 2014c). The association between poverty and education was evident, as the majority of respondents were illiterate or had low literacy (71%), with only 29% having attended primary and secondary

school (Oldewage-Theron & Slabbert, 2010). This finding is supported in other South African research: (i) Fair & Louw (1999) highlighted low literacy levels in caregivers of children needing ECCI in developing communities, and (ii) in a cross-sectional survey that assessed English literacy levels of 100 male and female adult patients in the age range 18-59 years at a primary health care clinic in an urban setting, Wasserman, Todd, and Wright (2010) found that 67% of the participants had low literacy levels, with older participants having lower school grades. The effect of poverty and limited education on parents' perceived need for and access to health services is present worldwide in affluent countries too, as illustrated in an American national survey of 38 866 parents in urban and rural homes (Porterfield & McBride, 2007). The study investigated parents' perceived need for and access to specialist physician services, therapy services and prescription medication for children with special health care needs. Prescription medication was identified by 87.9% of parents, followed by specialist physician services (51%), and therapy services (23.5%). Less than 75% of the children who needed therapy services actually obtained it. Parents' education levels influenced their ability to recognise the need for therapy services and limited income influenced parents' ability to access services needed (Porterfield & McBride, 2007). The researchers explained that lack of information or resources made it difficult for low-income parents to navigate access to health services. Thus, issues of poverty, education, literacy and culture play an important role in mediating parents' perception of disability and management through help-seeking.

Finally, an additional factor that mediates parents' perceptions of problems and help-seeking is their physical and mental health, which is compounded in the presence of factors already discussed (Kisanji, 1995; Baird & McConachie, 1995; NPC, 2011; Samuels et al., 2012). The ECI literature consistently recognises the significant effects that diagnosis of disability, parenting, family relationships and work demands have on parents' physical and mental health, specifically with respect to depression and denial (Harris & McHale, 1989; Singer & Irvin, 1989; Kisanji, 1995; Rossetti, 2001; Sloper, 1999; Dunst et al., 1988; 1994a; Hastings & Taunt, 2002; Saloojee et al., 2007; NPC; 2011; Hwenha, 2014; South African Speech-Language-Hearing Association, 2015). Risks are exacerbated when support from family members and the community is limited or absent, particularly for single parents and especially when poverty restricts access to basic resources (Kisanji, 1995; Baird & McConachie, 1995; Saloojee et al.,

2007; Samuels et al., 2012). Research generally shows that parents raising children with disabilities report increased levels of stress and negative emotions or depression as reflected in Table 2 (Baird & McConachie, 1995; Tonge et al., 2006; Saloojee et al., 2007; NPC, 2011). However, reports are conflicting and maybe attributed to contextual factors already discussed, since some studies indicate no significant differences between mothers of children with and without disabilities (Hastings & Taunt, 2002; Gowen, Johnson-Martin, Goldman & Appelbaum, 1989). Depression reduces individuals' motivation and inhibits problem-solving performance (D'Zurilla & Nezu, 1982; D'Zurilla & Nezu, 2010). Studies in ECI have found that maternal depression decreased levels of reciprocity and maternal sensitivity during mother-child interactions (Baird & McConachie, 1995; Rossetti, 2001; Hwa-Froelich, Cook, & Flick, 2008; Van der Linde et al., 2015). The latter would have a negative impact on mothers' capacity to recognise problems in early communication skills and to initiate help-seeking.

Denial, on the other hand, refers to parents' negation of information or experiences relating to the diagnosis or future implications of children's disabilities because of its traumatic nature (Rossetti, 2001; Livneh, 2009). The current literature conceptualises denial as a set of strategies comprising perceptions, emotions, thoughts and behaviours, which function in a dynamic, changing manner to manage stressors positively or negatively (Livneh, 2009). On the positive side, denial can buffer the stress and trauma surrounding the child's diagnosis of disability, giving parents time to assimilate information, maintain self-esteem and hopefulness, while working towards accepting the situation and using problem-solving strategies to mobilise relevant resources (Livneh, 2009). On the negative side, though, denial can be harmful to the child and family if it hinders parents in seeking help from ECCI services, sustaining participation and compliance with intervention, preventing parents from developing skills to manage long-term challenges and affecting interpersonal relationships with family, friends and ECCI professionals (Livneh, 2009). It is clear that health and well-being are important in enabling parents' to perceive problems and needs and to initiate and sustain help-seeking in ECCI. Early identification of challenges and access to relevant parent support ensure parents' sustained engagement in ECCI.

In summary, parents' perceptions of problems and needs in parenting young children with communication and established disabilities are significantly mediated by parents' beliefs,

values and knowledge regarding disability, communication skills and management. Disability legislation and policies and parents' culture, economic and social resources, education and literacy and their health play important roles in shaping parents' perceptions of problems and needs, with resultant varying effects on parents' help-seeking in affluent and less affluent developing contexts. The following section focuses on parents' causal attributions regarding disability that mediates parents' help-seeking.

### **2.3.1.2 Problem attribution**

Problem attribution refers to individuals' attributions or explanations of causes for problems experienced in everyday living (D'Zurilla, 1986; Peterson & Steen, 2002). Attribution theory suggests that establishing the cause of a stressful event (e.g. child's disability) is part of the process of finding meaning and imposing stability in people's lives, and is correlated with better psychological and physical health compared to dysfunctional responses based on denial (Taylor, 1983; Baumeister & Vohs, 2002). Individuals' beliefs and values underpin causal attributions, thus contributing to their interpretation of stressful events (Lazarus & Folkman, 1984; Taylor, 1993; Antonovsky, 1993; Elliott et al., 2002; Baumeister & Vohs, 2002). This process facilitates individuals' understanding of the problematic situation, which in turn mediates decision-making leading to positive or negative functioning, for example, whether to seek help or not (Antonovsky, 1993).

Causal attributions are derived from two factors: (i) the situation itself that provides an explanation for the problem, or (ii) the person's habitual way of making sense of events—referred to as the individual's explanatory style (Peterson & Steen, 2002). Family therapy research highlights that the individual's explanatory style may be positive/optimistic or negative/pessimistic based on how controllable the event or behaviour is perceived to be (Peterson & Steen, 2002; Hetherington et al., 1998). Research identifies a broad three-dimensional framework of individual attributions that mediate an individual's explanatory style and thereby, their social problem-solving behaviours, namely internal/external; stable/unstable and specific/global attributions (Peterson & Steen, 2002; Sluzki, 1992; Hetherington et al., 1998; Friedlander & Heatherington, 1998). Each dimension reflects positive and negative ends on a continuum. Internal attributions refer to factors within the person that are perceived to be

responsible for the problem (e.g. behaviour; traits; interests; abilities; deficits; personality style; physical, emotional or psychological states; illness or disability; motivation; attitude; beliefs; and values). External attributions refer to factors outside the person that are perceived to be responsible for the problem (e.g. situations; context; events; other people; authorities/systems; divine will, luck, or fate). Stable attributions relate to perceiving outcomes of the problem as long-lasting and not controllable/changeable, while unstable attributions relate to perceiving outcomes as transient and thus controllable/changeable. Finally, global attributions relate to perceptions that the outcomes of the problem affect many tasks/areas of functioning or contexts, while specific attributions refer to perceptions that outcomes affect particular tasks/areas of functioning or contexts.

A positive explanatory or attribution tendency assigns the cause of problems to specific external/environmental factors and/or relatively benign, transient or changeable personal factors. People displaying positive attribution tendencies are more likely to perceive problems as a normal part of life, approach problems and initiate problem-solving activities with confidence—resulting in positive coping. In contrast, a negative explanatory or attribution tendency ascribes the cause to internal, stable personal abnormalities or defects that have a global effect. The latter promotes negative self-evaluations, negative affect, avoidance tendencies and inhibition of problem-solving performance—giving rise to negative coping (D’Zurilla, 1986). Optimistic attributions generate positive meanings and emotions that broaden individuals’ cognitive and behavioural repertoires (Fredrickson, 1998, cited in Peterson & Steen, 2002; Baumeister & Vohs, 2002). The latter is significant in facilitating problem-solving ability and achieving effective, sustainable and versatile outcomes (D’Zurilla, 1986; Peterson & Steen, 2002).

In ECCI, parents’ causal attributions for problems experienced in parenting children with communication and established disabilities relate to the situation (i.e., children have disabilities, and/or parents’ limited access to parenting resources) and to parents’ habitual way of interpreting disability and/or situations. Thus, two critical issues that influence parents’ positive or negative attribution tendencies are their perceptions of the causes of children’s established and communication disabilities and their interpretations of what the disabilities mean for the child’s, parent’s and family’s well-being in terms of enabling or hindering the achievement of “personal goals and desired activities” (Elliot et al., 2002, p. 692; Sameroff & Fiese, 2000; Baird &

McConachie, 1995; Kisanji, 1995; Saloojee et al., 2007; Wegner & Rhoda, 2015). The latter, in turn, are pivotal in motivating parents to initiate and maintain help-seeking in ECCI.

The perceptions of parents with children with disabilities about the causes of problems experienced during parenting are derived from their beliefs regarding disability, which influence their values and interpretations of the child's disability (Sameroff & Fiese, 2000). The ECI literature reflects that parents' causal attributions and interpretations of disability are shaped by their socio-cultural context, comprising culture, religion, education and acculturation (Harry, 2002; Zhang & Bennet, 2001; Sameroff & Fiese, 2000; Friedlander & Heatherington, 1998; Kisanji, 1995; Baird & McConachie, 1995; McConkey, 1995; Wegner & Rhoda, 2015). To facilitate help-seeking in ECCI, it is crucial that parents' causal attributions for children's established and communication disabilities reflect a positive attribution tendency. In this respect, however, not all dimensions of the causal attribution framework proposed for effective social problem-solving are applicable for parents of children with disabilities.

The identification of the cause of problems experienced in parenting children with disabilities influences ECCI planning; it is understood from two perspectives: (i) the transactional model of causation (Sameroff & Fiese, 2000; Rossetti, 2001) and (ii) differentiation of the initial and maintaining causes of parenting problems (Björck-Åkesson et al., 1996). Firstly, the transactional model of causation places equal emphasis on the effects of the child's constitution (i.e. genetic organization) and environment (i.e. experiences provided by the family and broader social contexts) (Sameroff & Fiese, 2000; Rossetti, 2001). Developmental outcomes are seen as the combined product of the child and his/her experiences, with emphasis on reciprocal, dynamic interaction that changes over time (Sameroff & Fiese, 2000; Rossetti, 2001). Thus, although a child is born with an established disability such as cerebral palsy, experiences provided by the family and broader socio-political context play a critical role in facilitating positive developmental outcomes in areas compromised by the primary established disability, for example, communication or motor skills (Dunst, 2004; Rossetti, 2001; Sameroff & Fiese, 2000). Secondly, Björck-Åkesson et al. (1996), Sameroff & Fiese (2000), and Granlund et al. (2005) highlighted the need for professionals to differentiate between initial and maintaining causes of problems to facilitate intervention planning. The authors emphasise cause-effect relationships specific to maintaining factors as these can be manipulated during intervention to promote

positive outcomes. Attribution theory indicates that parents' perceptions of cause-effect relationships for the initial cause are just as significant in establishing the effectiveness of parents' coping and functioning, and is central in facilitating positive intervention outcomes (Lazarus & Folkman, 1984; Taylor, 1993; Antonovsky, 1993). Therefore, the theoretical focus on causal attribution in ECI moves beyond the establishment of cause-effect relationships, towards a transactional view of factors in the child and family that can be strengthened to facilitate positive functioning in the child and family.

It is clear that the positive and negative attribution tendencies associated with the three dimensions of internal/external, stable/unstable, and global/specific in social problem-solving are generally relevant for parents of children with chronic disabilities. However, while internal or external attributions are clearly related to negative and positive attribution tendencies respectively from a social problem-solving perspective, in ECI the relationship is not so clear (Peterson & Steen, 2002), since both attributions may be positive or negative for children born with established disabilities (Rossetti, 2001). The critical issue differentiating positive from negative attribution tendencies is the parents' ability to accept the initial cause (whatever it maybe), and choose to move forward by seeking appropriate assistance to manage the child's disability effectively, thereby enhancing the child's and the family's positive functioning within the context of the disability. The use of relevant emotion-focused (e.g. acceptance) and problem-focused (e.g. seeking ECCI) coping strategies would demonstrate positive attribution tendencies (D'Zurilla & Nezu, 1999, 2010; Beresford, 1994). However, if parents attribute the initial cause of the child's established disability to poor medical care during birth (an external attribution), and become fixated on blame or seeking retribution instead of pursuing intervention for the child, it would demonstrate negative attribution tendencies and identify the need for parent support. The literature on social problem-solving supports the need for parents to adopt a positive/optimistic approach to causal attributions to facilitate initiation and maintenance of help-seeking (D'Zurilla & Nezu, 1999, 2010).

Parents' beliefs regarding disability are therefore a key factor that challenges parents' causal attribution. As discussed in Section 2.3.1.1, studies indicate that parents' causal attributions occur on a continuum extending from traditionally cultural to varying levels of acculturation, which arbitrate parents' adaptation and positive functioning (McConkey, 1995;

Kisanji, 1995; Harry, 2002). For example, traditional attributions of disability in many Asian and African families in developed and developing contexts hindered coping as it engendered feelings of guilt/shame based on the extent of stigma or value that communities attached to the disability. These attributions include transgressions committed in a previous life, a form of divine punishment for past sins, evil spirits and blaming themselves for not following dietary and health care practices during pregnancy (Chan, 1992 cited in Zhang & Bennet, 2001; Cho et al., 2000; Peterson & Steen, 2000; Beuster & Schwär, 2005; Saloojee et al., 2007; Wegner & Rhoda, 2015). The perceived social stigma influences parents' help-seeking behaviour, with some parents hiding the child from neighbours or accessing help from a traditional healer, rather than from ECI professionals, whilst others specifically choose to access help from the ECI professional who was a stranger, rather than approach members from their informal social network (McConkey, 1995; Dunst et al., 1989; Li-Tsang, Yau & Yuen, 2001; Wegner & Rhoda, 2015). In addition, increasing levels of parents' education and acculturation influence attributions toward more contemporary western causes such as blaming traits, illnesses and external factors—which the literature identify as facilitative coping (Hetherington et al., 1998). Parents' lower levels of education and literacy in developing contexts do pose a challenge, as already discussed in Section 2.3.1.1 (McConkey, 1995; Kisanji, 1995; Baird & McConachie, 1995; Harry, 2002; NPC, 2011; Wegner & Rhoda, 2015 ). A comparative study of the adaptation of Korean and Korean American parents to their children with developmental disabilities illustrated the varying effects of acculturation and its positive or negative effects on parents' positive functioning (Cho et al., 2000). The study found that Korean parents followed traditional tendencies, attributed blame to themselves (e.g. not following relevant prenatal practices) with consequent negative effects on adaptation. The majority of Korean American parents had acculturated, followed the religious principles of Christianity, and attributed the cause to a divine plan that ultimately benefitted the child and family, facilitating parents' positive functioning (Cho et al., 2000). However, McConkey (1995) cautioned that a fatalistic acceptance of the disability may engender perceptions of limited control over disability outcomes, contribute to low expectations regarding the child's developmental potential and result in greater time and effort directed at physical care and protection, rather than accessing intervention.

Hastings and Taunt (2002) reviewed several studies of parents' and families' positive experiences of raising children with disabilities and concluded that many parents attributed and interpreted causes in ways that facilitated the family's positive functioning—for example, choosing not to blame themselves. A similar pattern is evident in studies reviewed in Appendix A with parents choosing to revise and reconstruct events positively (Larson, 1999; Scorgie et al., 1996, 1999; Scorgie & Sobsey, 2000). It is therefore evident that parents' causal attributions and interpretations of disability are diverse and play a significant role in motivating parents to initiate or maintain efforts in seeking help in ECCI, in addition to parents' perceptions of personal control.

### **2.3.1.3 Personal control**

Personal control is a perception about one's ability to act on the environment to obtain desired outcomes and is considered a critical motivator to access resources for survival (Thompson, 2002). D'Zurilla (1986) as well as D'Zurilla and Nezu (1999, 2010) utilize Bandura's concepts of outcome expectancy and self-efficacy expectancy to operationalise the process underpinning perceptions of personal control (Bandura, 2001). With respect to social problem-solving, outcome expectancy describes an individual's perception that a problem is solvable or controllable, whilst self-efficacy expectancy describes the belief that she/he is capable of solving the problem through individual effort (D'Zurilla, 1986; D'Zurilla & Nezu, 1999). Effective problem solvers have positive outcome and self-efficacy expectations, believing that problems are solvable or controllable and that they have the capacity to find solutions (D'Zurilla, 1986; D'Zurilla & Nezu, 1999, 2010). These perceptions reduce anxiety and facilitate individuals' coping in stressful contexts by initiating problem-solving coping behaviours and maintaining persistence or effort in the face of obstacles (D'Zurilla, 1986). In contrast, the perception of uncontrollability or low self-efficacy increases anxiety, avoidance behaviour and other maladaptive behaviours for ineffective problem-solvers (D'Zurilla, 1986). A study by Ross and Mirowsky (1989, cited in Thompson, 2002) found that persons with a strong sense of control are more likely to engage in problem-solving by determining the cause of a problem and taking

action, whereas those with a low sense of control use the ineffective coping strategy of avoiding the problem.

The concept of personal control receives significant attention in theories of coping, adaptation and positive functioning. Taylor's (1993) theory of cognitive adaptation states that establishing a sense of mastery or control over threatening events and enhancing one's self-esteem mediates adaptation. Similarly, Antonovsky (1993) indicated that perceiving a problem as 'manageable' through skilled use of individual, family and other resources is a prerequisite for successful coping. Additionally, if an individual is motivated to pursue coping actions without assurances of a positive outcome, the chances of comprehending the problem and its manageability are greater (Antonovsky, 1993). While some of life's problems can be easily changed, difficult problems may be a challenge requiring innovative ways of gaining control. Thompson (2002) discussed three strategies to gain control of difficult problems: (i) Being flexible and changing to attainable goals; (ii) identifying and cultivating other areas of control that are possible; and (iii) accepting and deriving benefit from the situation as it is. It is clear that individuals' expectations about problem outcomes and their ability to manage problems, even in difficult contexts, are important mediators of perceptions of personal control. The latter, in turn, mediates individuals' motivation to approach or avoid problem-solving.

For parents of children with communication and established disabilities, it is thus evident that their perceptions of control are critical in mediating motivation to initiate and sustain help-seeking in ECCI. Parents' expectations of control are important in two aspects: (i) The outcomes of disability and ECCI, and (ii) their capacity to manage parenting challenges and seek help. Firstly, with respect to outcome expectations, the ECCI literature reflects that parents' beliefs in two areas influence motivation: (i) Expected outcomes of established and communication disabilities and (ii) the ability of ECCI to control/change the expected outcomes. Parents are more likely to expect positive outcomes if they are: (i) Knowledgeable about the transactional model of child development, since this model foregrounds parents as important regulatory agents who can mediate positive outcomes in the social environment (Sameroff & Fiese, 2000). (ii) knowledgeable and realistic about the benefits of ECCI, derived through their own education or personal experience in seeing children with disabilities benefiting from ECCI (Kisanji, 1995); and (iii) living in a community that has a positive attitude toward people with disabilities

(Kisanji, 1995; McConkey, 1995, 2005; Wegner & Rhoda, 2015 ). The review of descriptive studies in Appendix A indicates that many parents gained control of their situations by using the strategies that Thompson (2002) identified for managing difficult problems. Parents expected positive outcomes for their children with disabilities and the received treatment, and their expectations were aligned realistically with the severity of the disability (Grant & Whittell, 2000; Scorgie & Sobsey, 2000). Kisanji (1995) emphasised the need for parents to have realistic expectations of intervention, since unrealistic expectations lead to dissatisfaction and decreased participation.

Secondly, with respect to self-efficacy expectations, parents' beliefs about their own capacity to improve the child's and the family's well-being by managing parenting challenges effectively, are crucial in motivating them to initiate and sustain help-seeking. Research indicates that caregivers' outcome and self-efficacy beliefs are correlated with positive mental and physical health, thus highlighting the buffering effect of personal control (Heller, 1993; Thompson, 2002, Barnett et al., 2003; Li-Tsang et al., 2001). Section 1.2 and family case studies in Turnbull et al. (1993) illustrate that most parents felt overwhelmed by the birth of a child with established disabilities. Studies about caregiver adaptation throughout the lifespan, identified factors that influence parents' self-efficacy and outcome expectations, including: children's ages, extent of cognitive, communication and behavioural problems that contribute to the type and severity of the disability, families' socio-economic and cultural context; parents' education and personalities; and normative developmental transitions such as birth, school and adolescence (Thompson, 2002; Heller, 1993; Sloper, 1999; Baird and McConachie, 1995; Rossetti, 2001). A brief discussion of research on some of the factors demonstrates the effects on parents' perceptions of outcome and self-efficacy, with subsequent influence on parents' help-seeking during ECCI.

In studies of children with mental disabilities, Heller (1993) found that when parents of young children received information and support from ECI professionals early on, they were generally more positive regarding outcomes compared to parents of older children and adults. Studies also found that caregivers' perceptions of self-efficacy and control were higher when: (i) children were younger, had fewer problem behaviours and lived at home; and (ii) families were from higher socio-economic backgrounds (Heller, 1993). These caregivers also spent more time

with the child, sought professional support and engaged more in therapy, although involvement decreased as the child grew older and treatment outcomes stabilized (Heller, 1993). Heller (1993) also found that caregivers' active involvement increased perceptions of burden but did not significantly affect caregiver depression. This finding was in contrast with cognitive adaptation theories, which reflected that families with a higher sense of self-efficacy perceived fewer burdens (Antonovsky, 1993). With respect to culture, Thompson (2002) described studies that indicated that people from less individualistic cultures might derive less benefit from individual-level perceptions of control, for example, Asian and African cultures. The finding implies that group-level perceptions of control would be important mediators of perceived outcome and self-efficacy expectations for parents in such contexts. Support for the argument is evident in cross-cultural research already discussed in Section 2.3.1.1 and Section 2.3.1.2, with research indicating that parents from backgrounds that stigmatize disabilities (e.g. traditional Asian and African cultures) and parents with lower education are generally more likely to perceive limited control. The research also foregrounds parents' acculturation as a dynamic factor mediating parent motivation to seek help. From a personality perspective, the specific effects of depression on parents' perceptions of personal control were emphasised, with studies showing that depression negatively influenced motivation through perceptions of decreased control and capacity (Thompson, 2002; Heller, 1993; Sloper, 1999). Similar negative effects on perceptions of personal control are evident in parents living in contexts of poverty (McConkey, 2005; Kisanji, 1995; Baird & McConachie, 1995; Hwenha, 2014; Wegner & Rhoda, 2015). Finally, Baird & McConachie (1995) and Wegner & Rhoda (2015) highlighted the critical impact of professionals' communication of the child's diagnosis on parents' perceptions of outcome and self-efficacy. They emphasised the need for relevant information and emotional support to foster positive expectations of personal control.

It is evident from the above that parents' perceptions of outcomes and self-efficacy are critical mediators of their perceptions of personal control in improving the well-being of children with communication and established disabilities. Based on social problem-solving theory (D'Zurilla, 1986; D'Zurilla & Nezu, 1999, 2010), parents who believe that the child's disabilities can be controlled through relevant ECCI and that they do have the ability to assist the child, are more likely to be motivated to initiate and maintain help-seeking in ECCI. However, research

findings discussed in Section 2.3.1.1 and Section 2.3.1.2 established the unique challenges that compound parents' perceptions and therefore their help-seeking efforts, especially for parents from traditional cultures and poor socio-economic contexts. The critical influence of parents' perceptions of causal attribution and personal control on their appraisal of problems and overall motivation toward help-seeking is considered next.

#### **2.3.1.4 Problem appraisal**

Problem appraisal relates to the concept of primary appraisal from the theory of stress and coping (Lazarus and Folkman, 1984) and refers to an individual's "evaluation of the significance of a problem for personal-social well-being" (D'Zurilla, 1986, p. 24). The significance of the problem is evaluated in terms of its physical, psychological, social and economic benefit or harm to individuals (D'Zurilla, 1986; D'Zurilla & Nezu, 1999, 2010). Perception of the problem as a benefit or challenge to well-being (e.g. opportunity for mastery, achievement), facilitates positive problem appraisal, which promotes approaching the problem and initiating planned, effortful problem-solving activities (D'Zurilla, 1986; D'Zurilla & Nezu, 1999, 2010). Positive appraisal is important for positive coping and adaptation (Heppner & Lee, 2002). In contrast, viewing the problem as harmful or threatening to well-being promotes anxiety and avoidance of the problematic situation, leading to maladaptive problem-solving behaviours and negative coping and adaptation (Heppner & Lee, 2002). The significance of problem appraisal for effective problem-solving and positive coping, adaptation and functioning is evident. As stated, theories of stress, coping and positive functioning conceptualise problem appraisal as the central component mediating individuals' positive or negative coping responses (Lazarus & Folkman, 1984; Antonovsky, 1993; & Elliot et al., 2002). Consideration of the appraisal or meaning-making process is warranted to understand individuals' appraisal of problems as a threat or challenge to well-being.

When confronted with a difficult situation, individuals initiate the appraisal process by establishing the situation's meaning for well-being (i.e. threat or challenge) to guide appropriate actions (D'Zurilla & Nezu, 1999, 2010). The literature reflects two critical issues that mediate the appraisal process. Firstly, Baumeister & Vohs (2002) state that when individuals' develop meaning they are motivated by establishing (i) purpose (i.e. connecting the present event with a

positive future event); (ii) values (i.e. using a sense of right and wrong to shape actions, thereby reducing feelings of distress such as guilt and anxiety); (iii) efficacy (i.e. believing that one can make a difference); and (iv) self-worth (i.e. believing that one is good or valued irrespective of circumstances). When individuals meet these four needs positively, difficult events are experienced as meaningful and are appraised as beneficial to well-being. Heppner and Lee (2002) stated that successful resolution of problems enhanced positive appraisals of one's problem-solving abilities. It is clear that the meaning-making process is likely to be mediated by individuals' perceptions of causal attribution and personal control (D'Zurilla & Nezu, 1999, 2010), when establishing purpose, value, efficacy and self-worth.

Secondly, Baumeister and Vohs (2002) indicated that different levels of meaning are ascribed when making sense of difficult problems. At low levels of meaning individuals try to make sense of the problem and in doing so, they focus on concrete, specific details to establish purpose, value, efficacy and self-worth. When the situation improves, they shift to higher levels of meaning and make sense of the problem by embracing broader family values, which enhance a sense of fulfilment and satisfaction. Both levels suggest a developmental progression in appraisal with low levels of meaning present at the onset of problems, progressing to higher levels when problems continue and individuals adapt to it. The appraisals will influence individuals' initiation and maintenance of problem-solving efforts. Baumeister and Vohs (2002) also highlighted the need for individuals to derive meaning from multiple sources (e.g. family, work, religion) to protect against feelings of meaninglessness when events in one source becomes stressful. This is similar to the strategy of cultivating personal control in other areas, where possible, during difficult situations (Thompson, 2002). In summary, meaning making involved in establishing purpose, value, efficacy and self-worth is central to the problem appraisal process, and it mediates individuals' appraisal of problems as challenges or threats. Individual's appraisals influence their motivation to initiate and sustain efforts in problem-solving.

In ECCI problem appraisal refers to parents' appraisal of problems experienced in parenting young children with communication and established disabilities. Problems may relate to parents' perceptions of the disabilities, and/or their limited access to parenting resources (as discussed in Section 1.2). Problems may be perceived as a threat or challenge to parents'

physical, psychological, social and economic well-being; based on social problem-solving theory, this appraisal is the most critical mediator of parent motivation to seek help from professionals (Thrush & Hyder, 2014; D’Zurilla & Nezu, 1999; Sloper, Knussen, Turner & Cunningham, 1991; Beresford, 1994; Wegner & Rhoda, 2015). Parents’ appraisal of problems as a threat or challenge is likely to be significantly influenced by their causal attributions and perceptions of personal control, as already discussed. A positive appraisal of problems as a challenge therefore implies that parents: (i) have a positive causal attribution tendency and accept whatever the initial cause of the problem is, (ii) choose to control factors that maintain problems that can be controlled, such as their lack of knowledge and skills in parenting children with disabilities; (iii) believe that formal support such as ECCI will enable parents to control factors that maintain parenting problems (e.g. feeding, communication); and (iv) believe that they have the capacity to access the support that they need to enhance positive functioning in the child, parent and family, within the context of the disability. A negative appraisal of problems as a threat, however, implies that parents: (i) have a negative causal attribution tendency and experience difficulty accepting whatever the initial cause of the problem is; (ii) view the disability and related factors as uncontrollable; (iii) believe that formal support such as ECCI will therefore not be able to help parents in controlling factors that maintain parenting problems (e.g. feeding, communication); and (iv) believe that positive functioning in the child, parent and family is not possible, due to the child’s disability and the associated stigma.

Parents’ appraisal of problems may therefore be viewed as the central variable of the problem orientation construct that influences parents’ decision to seek and sustain help-seeking efforts in ECCI. The review of studies on parents who function positively in managing children with disabilities clearly demonstrates that these parents make specific decisions with respect to their causal attributions and personal control, which facilitated positive appraisal and effective help-seeking (see Appendix A). For example, reframing meanings of the event to embrace paradoxes, accepting the situation quickly and taking control to identify and access resources (Scorgie et al., 1996, 1999; Scorgie & Sobsey, 2000; Larson, 1998; Grant & Whittell, 2000). Moxley & Haegart (1983) found that teaching parents to recognise small gains in treatment gave parents control in the intervention process (see Table 2). This recognition promoted parents’

positive appraisals and increased motivation to participate in home programmes. The strategy is supported by McConkey (1995).

The challenges that confront parents in developing contexts highlight the specific issues that they require support in, in order to appraise problems positively, for example, cultural beliefs which mediate attitudes towards disability (e.g., blaming the mother) and limited knowledge and skills in managing children with disabilities. It is critical that parents appraise the child's disabilities as a challenge that can derive benefits from ECCI, since this orientation motivates parents to initiate and maintain help-seeking from ECCI programmes.

### **2.3.1.5 Time and effort commitment**

Time and effort commitment refers to an individual's willingness to devote the necessary time and effort to problem-solving (D'Zurilla, 1986). Individuals who appraised themselves as effective problem solvers identified effort as a significant determinant of successful performance compared to those who considered themselves ineffective problem solvers (Baumgardner, Hellner & Atkin, 1986 cited in D'Zurilla & Nezu, 1999). Additionally, the time and effort that individuals commit to activities indicate the reinforcing value of the activities for the individual's well-being (D'Zurilla & Nezu, 1999). If the activity is highly valued, individuals are likely to approach problems, initiate activities of problem-solving, and persist if confronted with obstacles; but if the activity is not highly valued, then avoidance and a lack of time, effort, commitment and motivation are likely to be evident (D'Zurilla & Nezu, 1999, 2010).

The review of studies in Appendix A of parents who functioned positively in managing children with disabilities, demonstrates that parents committed time and effort to initiate and sustain help-seeking, to achieve effective, sustainable and versatile outcomes for their child (Rossetti, 2001). The review reflects that parents' commitment was again significantly influenced by other competing demands on the parents' time and commitment (e.g. poverty; work; care-giving to other family members), the value placed on communication skills and by parents' perceptions of control over the disabilities and access to the required resources to help the child. Parents' causal attributions and perceptions of control (i.e. outcome and self-efficacy) regarding established and communication disabilities are significant mediators of their decision to commit time and effort. Parents who adapt positively are willing to commit time and effort to

enhance their knowledge and skills in parenting children with disabilities by attending training programmes and to promote their physical and mental well-being by engaging in activities that bring relief from daily care-giving routines.

In conclusion, the five-dimensional framework of problem orientation provides a relevant, systematic framework to conceptualise and support parents' motivation toward seeking help in ECCI. While the theory of social problem-solving provides the overall framework for problem orientation, theories of coping, adaptation and positive functioning highlight the significance of the dimensions of problem attribution, personal control and problem appraisal for the field of disability. In particular, the dimensions of problem attribution and personal control are conceptualised as mediators in problem appraisal. The latter is important in identifying core dimensions for parent support. Key factors that currently challenge parents' adoption of positive orientations during help-seeking in ECCI and reflecting specific areas for support include knowledge of disability policies, cultural beliefs and values, education and literacy, poverty, and health.

The next section discusses the significance of the second stage of social problem-solving, namely, problem definition, in facilitating parents' help-seeking in ECCI.

### **2.3.2 Problem definition: facilitating parents' effective communication of problems and needs during help-seeking**

Problem definition is the first task at the behavioural level that is significant for successful problem-solving. A well-defined problem promotes the creation of relevant solutions and improves the effectiveness of decision-making in selecting and verifying the most appropriate solution for the context (D'Zurilla & Nezu, 1999, 2010). A well-defined problem contains essential features to describe the problem appropriately, which assists help-givers to maximize problem resolution. D'Zurilla (1986) emphasised that real-life problems were complex, due to vague, inaccurate, irrelevant information and/or unclear goals. The theory of social problem-solving identifies four essential attributes of well-defined problems, which form the conceptual basis for the stage of problem definition. These attributes translate to four critical principles that individuals need to follow to generate problems that are well-defined and formulated to optimize successful outcomes: (i) Gather relevant and factual information about

the problem and perceived solution, (ii) Identify solutions that are realistic and attainable. (iii) Organize information in a way that clarifies understanding of the nature of the problematic situation. (iv) Re-evaluate the importance of the problem for personal well-being after it has been defined and formulated (D’Zurilla & Nezu, 1999, 2010). Relevance of the problem definition construct for supporting parents to access the help that they need from ECI is discussed next, and a framework appropriate for ECCI is proposed.

The construct of problem definition is extremely relevant for parents in the role of consumer and decision-maker (Granlund et al., 2005). The construct relates to the first step of the collaborative problem-solving process when parents communicate the problems that they experience in parenting young children with communication disabilities secondary to established disabilities, and identify their perceived needs to cope with these demands. As stated in Section 1.2 and reflected in Figure 1, parents’ descriptions of problems and needs constitute the critical foundation for planning effective, sustainable and versatile intervention (Dunst et al., 1994a; Bernheimer & Weisner, 2007; Spagnola & Fiese, 2007). The literature on ECI broadly indicates that many parents are not skilled in communicating problems and needs effectively and therefore they require support in doing so (Dunst et al., 1994a; Granlund et al., 2005). Section 1.2 also reveals that, thus far, parent interventions in ECI have given limited attention to strengthening parents’ competence as information-providers; and instead, focused on enhancing professionals’ competence as information gatherers. The focus foregrounds professionals’ knowledge and control of the problem-solving process in comparison to parents, thereby hindering the essence of real collaboration. Woods and Lindeman (2008) proposed a reciprocal framework for parents and professionals to provide and receive information in ECI, which highlighted the important role of families as information providers during collaborative problem-solving. They emphasised that, for families to be effective information providers, they need to understand intervention in relation to their everyday routines and activities (Woods & Lindeman, 2008). However, the proposed intervention remains driven by professionals, since it does not enhance families’ competence as information providers specifically.

For ECI to be a truly collaborative problem-solving process, it is imperative that both parents and professionals are knowledgeable about the process and skilled in playing their respective roles. This implies that both need to have a shared understanding of the problem-

solving process that underpins assessment and intervention. However, there are two constraining factors. Firstly, although ECI approaches that are commonly used utilize a broad problem-solving frame in identifying problems and needs during assessment (e.g. Dunst et al. 1988; 1994a; Björk-Åkesson et al., 1996, Coufal, 1993; Shipley & McAfee, 2013), the approaches differ theoretically in identifying the essential attributes of problems and needs for effective, sustainable and versatile intervention planning. Secondly, all approaches are conceptualised and operationalised to aid professionals in gathering information for intervention planning. These approaches are therefore too complex to use in supporting parents from diverse backgrounds. The lack of an appropriate theoretical framework that outlines information that is central for effective, sustainable and versatile ECI planning and that is sufficiently flexible for use by professionals and parents, led to a broader review of the medical literature to identify contexts that confronted similar challenges.

Six critical reviews of patient-doctor communication during medical consultations highlighted the importance of quality problem-solving. The reviews reflected patients' dissatisfaction with treatments received and doctors' complaints of patients' poor communication of their problems and needs (Roter, Hall, & Katz, 1988; Anderson & Sharpe, 1991; Post, Cegala, & Miser, 2002; Cegala, 2003; Harrington, Noble & Newman, 2004; Kinnersley et al., 2008; Pictor, Lewin, McKinstry & Kaufman, 2011). It prompted the medical field to shift focus and not only promote the doctors' communication skills during medical consultations, but to also strengthen patients' communication competence in four areas that are important for patients to identify the treatment that they needed. The areas included providing information (e.g. concerns, symptoms), seeking information (e.g. asking questions), preparedness (e.g. making lists) and partnership (e.g. openness, trust) (Roter et al., 1988; Anderson & Sharpe, 1991; Post et al., 2002; Talen, Grampp, Tucker, & Schultz, 2008). Table 3 describes a sample of patient-communication intervention studies that illustrate the nature of support provided, recommendations made, and outcomes achieved in current research.

Table 3

*Intervention Studies to Enhance Patients' Communication During Medical Consultations*

Authors	Aim and method	Results and recommendations
Roter (1977)	<p>To increase patient involvement in medical consultations by enhancing patients' question-asking skills. Experimental and control group design with 123 poor African American patients and one health educator.</p> <p><b>Intervention:</b> One 10-minute face-to-face training by health educator before visit to physician who assisted patient in identifying and articulating questions. Control group received a 10-minute face-to-face session on clinic services.</p>	<p>Experimental group asked more questions in medical consultations than control group, but there were no differences in patient satisfaction. Experimental group experienced increased negative affect toward the physician.</p>
Greenfield, Kaplan & Ware (1985)	<p>To increase patient involvement in disease management by increasing their understanding of the medical process and decision-making. Effects on physician-patient interaction, patients' functional limitations due to health; patient satisfaction with care, preference for involvement in medical decision-making and level of knowledge of health were assessed, using a randomized control trial with 45 patients and 8 physicians.</p> <p><b>Intervention:</b> A 20-minute face-to-face training preceding visit comprising medical review, treatment algorithm, negotiation skills, rehearsal of techniques to overcome communication barriers, copy of medical record and treatment algorithm for visit. Control group received a 20-minute face-to-face training comprising education on medical illness and a copy of education material.</p>	<p>Training had a positive impact on some indicators of patient involvement. Experimental group showed increases in: (i) verbal acts per minute, (ii) positive and negative affect during interactions with physicians, (iii) active role and physical functioning, (iv) use of alternative strategies to seek information (e.g. indirect requests) rather than direct questions. No significant differences in satisfaction were noted between the groups, and increased general knowledge of the disease was evident in the control group but not in the experimental group. Further research was recommended to clarify specific aspects of physician's interpersonal style and its influence on patient's health and functioning, and the change process between patients' perception of control and better health outcomes.</p>
Anderson, DeVellis & Dèveles (1987)	<p>To examine whether observation of two types of video-recorded modelling displays of verbal behaviours (i.e. question asking versus self-disclosure), would differentially increase patients' communicative behaviours with providers. A pre-test-post-test experimental study of 150 patients (men, majority black with low to moderate education levels). Control group observed a video-recorded education</p>	<p>Participants in the experimental group spoke more than those in the control group. Participants who viewed the question-asking model were more verbal compared to the those who observed the disclosure model. Further research is recommended to assess generalizability of findings in real clinical contexts, with different providers, and the specific</p>

Authors	Aim and method	Results and recommendations
<p>Thompson, Nanni &amp; Schwankovsky (1990)</p>	<p>presentation, with no modelling.</p> <p>To examine the effects of two types of written communications in increasing patients' question-asking in medical consultations: (i) list of general health concerns (Study 1), and (ii) checklist of specific concerns and general message encouraging question asking (Study 2). White, middle- or upper-middle class private outpatients who were randomly assigned to experimental and control groups. Dependent variables measured included number of questions asked, patient and doctors' satisfaction with visit, patient anxiety during visit, length of visit, patients' perceptions of control and confidence in understanding information, accuracy of recall of information and extent to which patients asked intended questions.</p>	<p>communicative behaviours that need to be taught to patients during disclosure.</p> <p><b>Study 1:</b> Experimental group asked significantly more questions and were significantly less anxious than the control group. No differences in the groups were found for patients' and doctors' satisfaction with the visit and the amount of time the doctor spent with each group.</p> <p><b>Study 2:</b> The two interventions were equally effective in increasing patients' asking of questions, perceptions of control and satisfaction. Further research to identify mechanisms responsible for the positive effects is recommended.</p>
<p>Lewis, Pantell &amp; Sharp (1991)</p>	<p>To develop and test a communication intervention to help parents, physicians and children recognise and overcome communication difficulties, and promote children's development as competent participants in health care. A randomized experimental and control design with 56 physicians and 141 parent-children dyads.</p> <p><b>Intervention:</b> Brief videotapes targeting children, parents and physicians that urged participants to consider goals of the visit, long-term goal for the child as a competent participant in health care, modelling of relevant interpersonal and communication skills, and research evidence supporting child-inclusive model of paediatric communication.</p> <p>Control group watched an educational video that was not specific to the intervention goal.</p>	<p>The brief intervention increased children's participation with substantive initiations and responses during visits, acquisition of information, better rapport with physicians and preference for an active role in health care. Physicians in the experimental group discussed a higher percentage of recommendations with the child and parent compared to the control group. Significant differences noted in parent and physician satisfaction with visits. Further research is recommended to identify specific intervention components that explain findings.</p>
<p>Frederikson &amp; Bull (1995)</p>	<p>To test the effects of a patient education leaflet on patients' communication during medical consultations. A quasi-experimental design was used with 80 private outpatients who were randomly assigned to an experimental and control group (40 in each group).</p> <p><b>Intervention:</b> Patient communication leaflet given to experimental group before medical consultation. Doctor was blind to study's aim and rated patient's communication after the visit as good, average or poor.</p>	<p>Experimental group showed significantly more 'good' communication, consultations were more efficient and did not have more time, effort or cost implications for the doctor. Findings reflect significant association between reading the leaflet and good communication. Further research is recommended to expand the design and complexity of measurement, including assessments from doctor and patient, over longer period.</p>

Authors	Aim and method	Results and recommendations
McCann & Weinman (1996)	<p>To investigate whether a simple written leaflet would enhance patient participation and satisfaction during medical consultations. The effects of psychological (self-efficacy, locus of control), socio-demographic and doctor's responses to consultations were examined. Two-group experimental and control design with 120 outpatients.</p> <p><b>Intervention:</b> Information leaflet handed out prior to consultation, encouraging patients to identify and clearly state concerns, perceived causes and treatment, and to ask questions. The leaflet provided dietary advice. Randomized assignment of leaflets to groups.</p>	<p>Intervention showed positive trends. Significant increase in length of consultations and number of questions asked by experimental group. No significant increase in patients' satisfaction with interview or doctor's ratings of anger or sympathy. A non-significant trend for doctor to provide higher ratings for understanding communication of experimental group. Psychological measures of self-efficacy and locus of control were not significant in differentiating patients' participation. Further research is recommended to explore intervention effects on other aspects of consultation process, to examine non-verbal communication via video-recordings and the mediating effects of doctor's consultation style and patient's individual differences and to develop sensitive measures to assess patients' self-efficacy and locus of control.</p>
Cegala, McClure, Marinelli & Post (2000)	<p>To test the effectiveness of a training booklet in enhancing patients' communication skills in seeking, providing and verifying information during medical consultations. An experimental design with random allocation of 150 patients to two treatment groups and a control group and 25 physicians (majority white).</p> <p><b>Intervention:</b> Two interventions comprised exposure to training booklet and summary sheet (trained group), and a summary sheet (informed group).</p>	<p>Trained patients were cognitively and communicatively engaged in consultations to a greater extent than informed and untrained patients. They were effective and efficient in seeking information, provided more detailed information about symptoms, verified information by summarizing and exhibited more control during interactions. Further research is recommended to identify optimal methods of training patients' communication skills, and the effectiveness of training booklets under routine clinical conditions.</p>
Alegría et al. (2008)	<p>To develop and evaluate a patient's self-reported activation and empowerment strategy to increase patients' question-asking and decision-making in mental health care. A pre-test-post-test nonrandomized comparison group design with 221 patients from two community mental health clinics that served mainly minority populations.</p> <p><b>Intervention:</b> Right Question Project-Mental Health (RQP-MH) (Alegría et al., 2008) training occurred over three 30-minute individual sessions. Each session occurred prior to a visit to the health care provider. Participants were</p>	<p>Compared to the comparison group, intervention participants were over two times more likely to be retained in treatment, over three times more likely to have scheduled at least one follow-up visit in the 6 month period, and demonstrated 29% more attendance to scheduled visits. Training was significant for patient activation but not for self-reported patient empowerment. Some providers felt challenged by patients' activation and empowerment. Recommendations included adding</p>

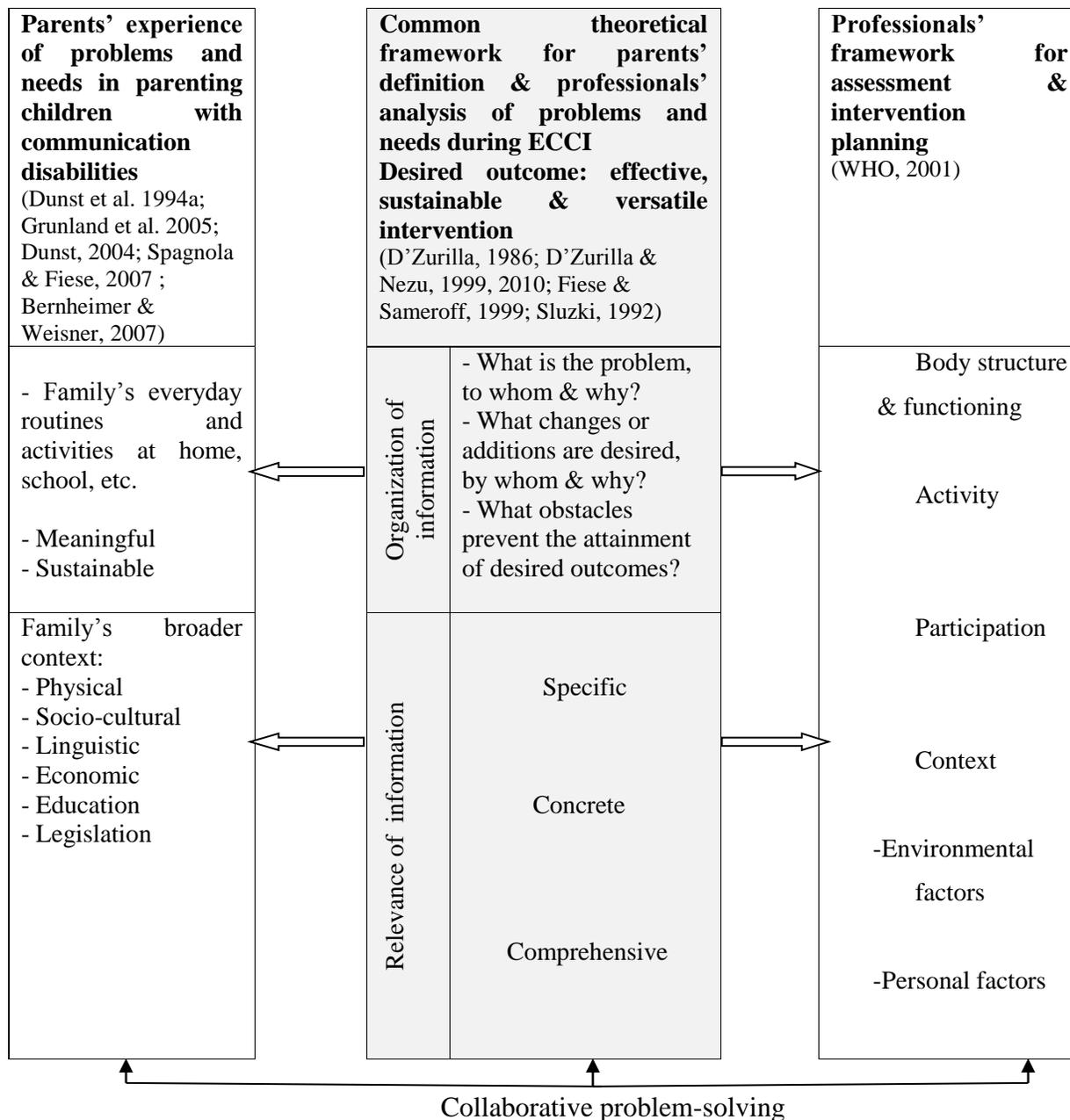
Authors	Aim and method	Results and recommendations
	<p>taught to identify questions that helped them consider their role during intervention, the process and reasons behind decision-making and empowerment strategies to better manage their care.</p>	<p>a provider component to intervention and a greater focus in developing patients' confidence and control in decision-making to facilitate patient empowerment.</p>
<p>Haskard et al. (2008)</p>	<p>The first study to assess the effects of a communication skills training programme for physicians <i>and</i> patients (18 years and older). Training outcomes involved physicians' perceptions of practice stress, life satisfaction, and satisfaction with medical visit, and ratings of physician-patient interaction; and patients' perceptions of information-giving, health behaviour counselling, choice and control in decision-making, and overall satisfaction. Study involved 2196 patients in interaction with 156 physicians. Physicians were randomized into one of four experimental treatment groups in a 2x2 between-subjects analysis of variance (ANOVA) design. Four conditions included physician trained, patient trained, physician and patient trained, neither physician nor patient trained (control group).</p> <p><b>Intervention:</b> Physician training included three 6-hour interactive workshops done over three months to increase communication skills, relationship with patient and healthy behaviour changes. Three 30-45 minutes coaching sessions reviewed audiotaped patient visits. Patient training was a 20 minute waiting room pre-visit intervention in the second month only, to listen to an audio CD with accompanying guide-book to plan and organize concerns and questions regarding treatment, follow-up care, medications, and referrals. Outcomes were measured at three points (i.e. before and after training, and six months thereafter).</p>	<p>Physician training indicated statistically significant effects on their explanations and information-giving, health behaviour counselling of patients, satisfaction in obtaining "detailed physical examinations", and connected-sensitive communication. Satisfaction with interpersonal aspects of their professional lives decreased. Attributed to recognition of limitations in their established interactional patterns with patients and the challenges involved to make changes.</p> <p>Patient training effects were limited to physician satisfaction with data collection process during the medical visit. Attributed to the reduced time given to patient training compared to physician training.</p> <p>Recommendations included the training of both patients and physicians for best communication and treatment outcomes; and measurement of broad-based outcomes of psychosocial interventions (e.g. physician stress and life satisfaction), as done in this study.</p>
<p>Roter et al. (2012)</p>	<p>To evaluate patient and physician computer-mediated communication skill training on participants' report of skill use and patient satisfaction. A pre-test-post-test randomized patient and non-randomized physician group design was implemented in parallel with 194 patients and 29 physicians.</p> <p><b>Intervention:</b> Separate interactive video clips demonstrating patient-centred communication skills, which were developed using the LEAPS framework (listen, educate, assess, partner and support).</p>	<p>Significant and parallel increases in both patient and physician reported use of patient-centred communication skills (i.e. identification of problems/concerns, information exchange, treatment adherence, shared decision-making and interpersonal rapport); and increased patient satisfaction with communication-related visit goals. Findings indicated that communication skills can be taught effectively to patients and physicians using</p>

Authors	Aim and method	Results and recommendations
		computer mediated intervention. The interventions are cost and time effective and may increase patient and physician motivation to participate in training.

A critical review of the studies in Table 3 indicated that interventions generally improved patients' active participation during medical consultations. The benefits of patient-communication interventions in facilitating effective treatment outcomes are thus relevant and could be applied in ECCI. However, interventions lacked a common theoretical framework to conceptualise patients' communication during medical consultations (Anderson et al., 1987). This is evident in two aspects. Firstly, in the arbitrary selection of intervention goals with undue emphasis given to supporting patients' information-seeking skills (i.e. question-asking), compared to skills in information-providing, preparation for consultations, and partnership building (Anderson & Sharpe, 1991; Post et al., 2002). Only five studies specifically targeted patients' functioning as information providers, namely; Frederickson and Bull (1995), McCann and Weinman (1996), Cegala et al. (2000), Haskard et al. (2008), and Roter et al. (2012). However, the lack of theory contributes to interventions that do not integrate the roles of patients and professionals in treatment planning, so that patients' selection and communication of information facilitates professionals' understanding of problems and needs, and thereby intervention planning. Secondly, the mutual functioning between patients' orientations (e.g. personal control and self-efficacy) and their communication during consultations received inadequate recognition (Thompson et al., 1990; McCann & Weinman, 1996 & Cegala et al., 2000). The critical need for a robust theoretical framework to support parent-communication interventions is clear.

The construct of problem definition is robust and offers a simple yet versatile theoretical framework to conceptualise and operationalise parents' and professionals' collaborative problem-solving during ECI. This study consolidates the four principles underlying well-defined problems for social problem-solving into two principles that are relevant for parent-professional communication in ECCI, namely, (i) organization of information and (ii) selection of relevant information. These two principles are the central coordinates of the proposed theoretical framework of problem definition in ECCI. Similar to the construct of problem orientation, the construct of problem definition appears to characterize a multidimensional construct in structure (Section 2.3.1) (Law & Wong, 1999). However, the theory of social problem-solving neither defines it as such, nor specifies the nature of the relationships among the four principles (D'Zurilla & Nezu, 1999, 2010). Therefore, it is not possible to identify the relationship of the

two consolidated principles proposed, in order to establish which of the two was critical to achieve a well-defined problem. In the absence of theoretical support and the significance of the two principles, both are deemed equally important for achieving well-defined problems. The framework is applicable to parents and professionals and provides a common systematic process that illustrates (i) How parents should communicate information about their problems and needs in order to access intervention that meets their needs; and (ii) How professionals should gather and understand information about parents' problems and needs in order to plan interventions that are effective, sustainable and versatile in meeting parents' needs. The proposed framework integrates research and theory on assessment and intervention planning from diverse fields. The overall framework is drawn from social problem-solving theory in the field of psychology (D'Zurilla & Nezu, 1999, 2010) and is supported by theories from ECI and ECCI (Bronfenbrenner, 1986; Dunst et al., 1988, 1994a; Dunst, 2004; Björk-Åkesson et al., 1996; Grunland et al., 2005; Rossetti, 2001; Gallimore et al., 1996; Bernheimer & Weisner, 2007; Spagnola & Fiese, 2007), health and disability (World Health Organization, 2001), narratives in socio-linguistics (Fiese & Sameroff, 1999; Sluzki, 1992), and patient-doctor communication in medicine (Talen et al., 2008; Platt, 2008; Street, 2007; Kalbfleisch, 2009). The framework addresses the challenges of current ECI collaborative problem-solving approaches already discussed, and integrates parents' orientations to problems and needs within current ECI assessment and intervention processes. Figure 2 illustrates how the main theoretical framework of problem definition provides a common context and promotes positive outcomes in collaborative problem-solving during ECCI; whilst Table 1 contextualizes the framework from the parents' perspective during ECCI.



*Figure 2* Theoretical framework to facilitate parents' and professionals' definition of problems and needs during ECCI

The following section discusses the relevance of the two principles in facilitating parents' help-seeking from professionals during ECCI, as proposed in the framework. Factors that currently challenge parents' use of effective problem definition skills are identified, especially for parents from diverse cultural, linguistic and socio-economic backgrounds. In this way,

specific issues that contribute to parents' dissatisfaction with ECCI are recognised, in order that relevant parent-communication interventions may be planned and provided. The first principle guiding how parents should organize information is discussed next, followed by the principle of how parents should select relevant information when communicating problems and needs during ECCI.

### **2.3.2.1 Organization of information to facilitate ECCI planning**

According to the social problem-solving theory, when information about problems is organized systematically in relation to perceived discrepancies between present and desired conditions, it enables problem solvers to understand the nature of the problem, and thereby generate effective solutions (D'Zurilla & Nezu, 1999, 2010). Social problem-solving theory thus advocates that individuals organize and communicate information in three steps when defining and formulating problems, namely, (i) What present conditions are unacceptable, to whom and why; (ii) What changes or additions are desired, by whom and why; and (iii) What obstacle/s prevent the individual from attaining the desired condition (e.g. emotional obstacles; information, ability or skill deficit; ambiguity, uncertainty or conflicting demands) (D'Zurilla & Nezu, 1999, 2010). These three steps facilitate the generation of relevant solutions in two ways (D'Zurilla, 1986; D'Zurilla & Nezu, 1999). First, it ensures that there is a clear differentiation of the problem in step one from the need in steps two and three. This differentiation enables problem solvers to gather the required information pertaining to each variable, and to then assess the relationship between both for effective resolution. The relationship is assessed by analysing three issues regarding needs, namely; (i) The nature of identified needs (i.e. whether problem or emotion focused), (ii) How realistic or attainable the needs are, and (iii) Whether the identified needs will contribute to satisfactory resolution of the problem. Second, the framework differentiates real problems from sub-problems by establishing causal attributions (e.g. what caused the problem?), and identifying general problems by using 'why' questions (e.g. why is the problem important?). The latter clearly establishes the mutual influence of individuals' orientations to problems and their definitions of problems during problem-solving (D'Zurilla & Nezu, 1999). Social problem-solving theory therefore provides a simple three-step framework

that organizes descriptions of problems and needs in a way that facilitates the problem solver's understanding, so that relevant solutions are identified.

The three-step framework for organizing information during social problem-solving provides a relevant common structure for parents and professionals to collaborate during ECCI to achieve effective, sustainable and versatile outcomes. For parents, the framework presents a systematic process to organize and communicate information about the problems and needs that they experience in parenting young children with moderate to severe communication disabilities. The need for patients to present information in an organized manner is highlighted in the medical literature (Talen et al., 2008). The ECI literature indicates that the desired goal of most parents is to construct and maintain meaningful, daily routines that promote the child's development and functioning and the family's quality of life (Gallimore et al., 1996; Granlund et al., 2005). The three-step sequence enables parents to communicate their problems and needs in a format that will facilitate professionals' understanding of the desired goal. Professionals' understanding promotes their capacity to use their expert knowledge and skills to identify intervention methods that achieve the desired goal (Talen et al., 2008). Intervention methods refer to peoples' actions, manipulations of the environment or assistive technology (Granlund et al., 2005). To be effective, sustainable and versatile, intervention methods must therefore enable parents to construct and maintain meaningful daily routines and activities (Gallimore et al., 1996; Alant, 2005a).

For professionals, the three-step framework is critical for planning effective, sustainable and versatile intervention because it elucidates two issues that receive inadequate consideration in current collaborative problem-solving approaches in ECI (Dunst et al., 1988, 1994a; Björk-Åkesson et al., 1996; Granlund et al., 2005; Coufal, 1993). Firstly, the framework enables professionals to follow a systematic process in gathering specific information about problems and needs that are crucial for successful intervention planning. The framework therefore facilitates a clear distinction in understanding problems versus needs. Secondly, the framework enables professionals to follow a systematic process in evaluating parents' needs in relation to identified problems. Thus, the problem-solving framework provides a mechanism for information-processing that is central to the clinical decision-making process. The evaluation establishes the nature of intervention required (i.e. child or parent/family focused), whether the

needs are realistic and attainable (e.g. expectations regarding established disability, parents' socio-economic status), and whether the needs identified will resolve the problems to the parent's satisfaction. To facilitate the latter, parents' orientations towards initial and maintaining causes of problems are explored, as discussed in Section 2.3.1.2; and parents' explanations are also explored to identify why the problem is considered a problem and why the need identified is considered an appropriate solution to the problem. The answers to the latter two questions should ideally relate to the parents' overall goal. As stated, in ECI parents' problems relate largely to factors that are perceived to hinder parents from their desired goal of constructing and maintaining meaningful, daily routines that promote the child's development and functioning and the family's quality of life (Gallimore et al., 1996; Granlund et al., 2005). Therefore, identified solutions should facilitate parents' attainment of their desired goal. Granlund et al. (2005) indicated that the collaborative problem-solving process facilitated a negotiation and co-construction of problems and needs between parents and professionals, so that desired goals were realistic and attainable from the child and environment perspective.

It is therefore evident that the proposed three-step framework for organizing information about problems and needs provides a common basis from which parents and professionals can collaborate during assessment and intervention. The second principle underpinning effective problem definition is discussed next, and specifies the nature of information that parents should provide in each of the three proposed steps.

### **2.3.2.2 Relevance of information to facilitate ECCI planning**

It is important that parents provide professionals with information that is relevant for planning effective, sustainable and versatile interventions (Alant, 2005a). Social problem-solving theory suggests that relevant information would facilitate professionals' understanding of the problem, which is critical for intervention planning (D'Zurilla & Nezu, 1999, 2010). Therefore, identifying core principles that make information relevant is important for supporting parents in providing relevant information during problem definition in ECCI. The theories of social problem-solving (D'Zurilla & Nezu, 1999, 2010) and family narratives (Fiese & Sameroff, 1999, Sluzki, 1992) are used to propose three principles that underpin relevant problem definitions for ECCI, namely, the need for definitions to be comprehensive, specific, and

concrete. The significance of each principle in facilitating relevant information for effective, sustainable and versatile ECCI planning is discussed.

Problem definitions that are **comprehensive** contain significant information that is presented coherently to facilitate professionals' understanding of the problem and their evaluation of (i) the fit between problem and need and (ii) whether needs are realistic and attainable (Fiese & Sameroff, 1999; D'Zurilla & Nezu, 1999, 2010). Coherent information implies synthesized and sequenced descriptions that contain clear beginning, middle and end parts (Fiese & Sameroff, 1999). For ECCI, coherent problem definitions are achieved in two ways, namely (i) by organizing information in the three steps proposed in section 2.3.2.1, and (ii) by describing the problem from a historical context to include onset, development and current status of the child's communication disability and other associated problems (e.g. poverty) (Sluzki, 1992). Current ECI assessment approaches access the latter by requesting parents to 'tell their story' or to 'describe a typical day in the family' (Bernheimer & Weisner, 2007; Spagnola & Fiese, 2007; Dunst & Deal, 1994b; Woods & Lindeman, 2008). In telling the story, however, the principles regarding **specific** and **concrete** information are crucial for facilitating decision-making and for the identification of attainable and realistic solutions (D'Zurilla & Nezu, 1999, 2010). Social problem-solving theory operationalises both principles as task and socio-behavioural information (D'Zurilla & Nezu, 1999, 2010). Task information describes the demands and requirements of various duties that must be performed in the person's different roles in order to function effectively, whilst socio-behavioural information portrays behavioural characteristics of persons involved in the tasks (including the problem solver) in terms of beliefs, values, goals, feelings, actions and words (D'Zurilla & Nezu, 1999, 2010). Applied to ECCI, specific information relates to children with communication and established disabilities and parents' role as caregivers in implementing tasks involved in creating meaningful, sustainable daily activities and routines that incorporate the needs of both children and families (Gallimore et al., 1993). Parents' descriptions of problems and needs that include examples from the families' daily activities and routines ensure that information is concrete (Spagnola & Fiese, 2007; Bernheimer & Weisner, 2007). The World Health Organization's (WHO) model of International Classification of Functioning, Disability and Health, commonly known as ICF, provides a relevant, standard, universally applicable conceptual framework to support parents in

understanding the nature of information that they need to be specific and concrete about, when accessing ECI from professionals (WHO, 2001).

The ICF is a multidimensional framework that measures individuals' health and functioning in society and is widely used in ECI research and practice nationally and internationally (WHO, 2001; Björk-Åkesson, Granlund & Simeonson, 2000; Alant & Lloyd, 2005; Nijhuis et al., 2008; Harty, Griesel & van der Merwe, 2011). It is based on the biopsychosocial theory of health and one of its functions is to document individual and environmental factors that restrict and enhance individuals' functioning and performance in everyday settings (WHO, 2001). While the ICF framework is limited in facilitating clinical decision-making for ECI planning (as proposed in the three-step framework of social problem-solving theory in Section 2.3.2.1), the framework does provide a comprehensive, systematic framework for professionals to gather and process specific and concrete information on individuals and their environment for intervention planning. The framework thereby operationalises the principles underpinning effective problem definition within the context of ECCI. The ICF outlines four factors that provide significant information about problems and needs at the level of individuals and the environment, to facilitate effective, sustainable and versatile intervention planning, namely, (i) body structure and functioning; (ii) activity and activity restrictions, (iii) participation and (iv) context that includes personal and environmental factors (WHO, 2001).

For ECCI each factor elucidates specific and concrete information about parents' problems and needs in parenting children with communication and established disabilities as follows: Body structure identifies anatomical parts of the child's body and its components (e.g. face, mouth, lips, etc.) that maybe impaired; body functioning considers physiological functions of body systems, including psychological functions (e.g. breathing, swallowing, thinking, etc.) which may also be impaired; activity describes the child's execution of tasks or actions in everyday activities and routines, and limitations thereof (e.g. talking, eating, etc.); participation portrays the child's active involvement in the family's daily routines and activities and restrictions encountered (e.g. expressing needs, helping with chores, etc.); and, lastly, context depicts the family's daily physical, social and attitudinal environment from two perspectives, namely, (i) personal (e.g. gender, age, education, culture, etc. of the child and family) and (ii)

environmental (e.g. legislation, physical terrain, etc.) (WHO, 2001; Shonkoff & Meisels, 2000; Rossetti, 2001; Spagnola & Fiese, 2007; Bernheimer & Weisner, 2007). It is evident that problem definitions that are relevant for ECI should contain comprehensive, specific and concrete information derived from the ICF, to facilitate professionals' information processing and thereby understanding of parents' problems and needs.

The preceding discussion clearly demonstrates the significance of the two principles in generating problem definitions that would facilitate effective and sustainable intervention planning for ECI broadly, and ECCI specifically. As stated, however, many parents are not skilled in communicating their problems and needs effectively to professionals. A review of the literature on patient or parent-professional communication identified the following factors that may challenge parents' problem definition skills during ECCI, and these reflect crucial areas for parent support (Table 1). The challenges include parents' confidence in communicating with professionals; their beliefs about the role of parents and professionals during the help-seeking and help giving process, the process of help-seeking and help-giving, parents' beliefs about the benefits of ECI, their mental health and their role in family decision-making. Each challenge is discussed briefly.

Firstly parents' confidence in communicating with professionals is influenced by their education, socio-economic status, age; culture, language and their knowledge and skill in communicating problems and needs to professionals to access help. Parents who have lower education levels come from lower socio-economic groups, are older and do not share the language and culture of professionals, are generally not confident in communicating with professionals, thereby limiting the information that is provided during help-seeking (Harry, 2002; Alant, 2007; Kalbfleisch, 2009; Hentz & Ellis, 2010). The discussion in Section 2.3.1.1 has already highlighted important issues relating to education, literacy, age, poverty and culture in developing and developed countries; Hentz & Ellis (2010) emphasised the significance for poor health literacy, which includes knowledge and communication of health problems. The pattern of cultural and linguistic mismatch between parents and professionals, however, is not the same in developed and developing countries. In contrast to developed countries, the majority of ECI professionals in some developing countries come from minority racial and cultural groups, as is evident in South Africa (Fair & Louw, 1999; Moodley, Louw & Hugo, 2000; Hentz

& Ellis, 2010; Kathard & Pillay, 2013; Kathard & Moonsamy, 2015). Limited access to interpreters and lack of skills in creating enabling and empowering relationships with parents from these contexts also compound professionals' access to relevant information for intervention planning (Dunst et al., 1994a; Harry, 2002; Moodley et al., 2000; Zinkin & McConachie, 1995; Woods & Lindeman, 2008; NPC, 2011; Samuels et al., 2012). Lastly, parents may not be knowledgeable or skilled in organizing and presenting their problems and needs effectively to enable professionals to understand their problems and provide the help that they require. D'Zurilla & Nezu (1999) indicate that individuals are expected to learn these skills as they develop social competence (D'Zurilla & Nezu, 1999). Research in America found that irrespective of education and literacy levels, between 12% to 26% of the American population aged 16 and older, lacked health literacy skills, including help-seeking (Hentz & Ellis, 2010; Wagner, Steotoe, Wolf, & Wardle, 2009). The number for developing countries like South Africa would be greater when considered in relation to the discussion in Section 2.3.1.1.

Secondly, parents' beliefs about the roles of professionals and parents during help-seeking and help giving may also influence the provision of information. Research found that parents or patients with poor knowledge about ECCI (i.e. benefits of intervention, role of parent in facilitating children's communication in everyday routines, the transactional approach, the principles of family-centred intervention), were likely to adopt a passive role during help-seeking and were also likely to consider the professional as the expert who did not need much information about their problems or needs (Rossetti, 2001; Dunst et al., 1994a; Woods & Lindeman, 2008; Wegner & Rhoda, 2015). Alternatively, if parents did not believe that ECCI could help the child and family, they would be reluctant to invest time and effort in providing detailed descriptions of concerns (Rossetti, 2001; Wegner & Rhoda, 2015). Parents' poor knowledge of the roles of ECI professionals (as seen in the study by Brodin and Molosiwa, 2000 in Section 2.3.1.1), may also hinder their ability to provide information that is relevant for specific professionals. The busy work schedule of professionals was a further factor that prohibited some patients from providing detailed information, because they did not want to waste the professional's time (Beisecker & Beisecker, 1990; Hill, 2011). Thirdly, the nature of the ECI process requires parents to share personal information during the case history phase of assessment, before they have had time to develop a trusting relationship with professionals

(Woods & Lindeman, 2008). Talen et al. (2008) indicated that patients provided critical information at the end of interviews, which possibly reflects when they felt secure to share more information with professionals. Kalbfleisch's (2009) study on the indigenous American population found that patients were not keen to provide self-information until trust was established with the professional. Fourthly, parents who are depressed, anxious or in denial of the child's disability (as discussed in Section 2.3.1.1), are unlikely to provide relevant information in an organized manner. Finally, if cultural traditions disregard the primary caregiver (e.g. mother or grandmother) as a decision-maker in the family, it may limit their ability to provide the relevant information needed for effective and sustainable intervention planning (McConkey, 1995; Kisanji, 1995; Thrush & Hyder, 2014; Wegner & Rhoda, 2015). The challenges discussed highlight the significant effect that parents' orientations have on their ability to provide relevant and organized information when communicating problems and needs during ECI. Parents' poor knowledge of the key principles that underpin effective communication during help-seeking, emphasises the need for parent support.

To summarize, the two-dimensional framework of problem definition provides a relevant and systematic format to conceptualise and support parents' communication of their problems and needs when seeking help from ECI professionals. The challenges discussed clearly indicate why parents may not be skilled in providing relevant and organized information for intervention planning and highlights specific areas for parent support. The need for professionals to create a nurturing and trusting environment that facilitates parents' communication is also identified as a critical variable for developing parent support programmes.

## **2.4 Summary**

This chapter conceptualised help-seeking as a problem-solving coping strategy and proposed a theoretical framework of problem orientation and problem definition to facilitate parents' help-seeking during ECI. The framework utilizes key principles of effective problem-solving to propose how parents should approach and communicate their problems and needs to professionals in order to access the help that they need to parent young children with moderate to severe communication disabilities. In doing so it provides a structural mechanism for supporting parents' help-seeking, beginning with parents' orientation to problems and proceeding to

parents' definition of problems. Factors that currently challenge parents' orientation to problems and their communication of problems and needs are identified and the mediating effect of parents' orientations on their problem definitions is evident. Finally, the core principles that underpin positive problem orientation and effective problem definition and the specific areas that hinder parents' positive functioning during help-seeking (as identified in the third and fourth columns of Table 1), constitute the core content of parent support programmes. Further training issues relating to principles and strategies are discussed in the next chapter.

## **CHAPTER 3**

### **RESEARCH METHODOLOGY**

#### **3.1 Introduction**

This chapter outlines the research methodology used in determining whether Problem Orientation and Definition (POD) training can facilitate parents' orientation to and definition of problems when accessing ECCI for children with moderate to severe communication disabilities. The chapter presents the research question, aim and sub aims and the research design that is most effective in addressing the challenges of intervention research under natural conditions. The research design was applied in the pre-experimental and experimental phases; it included measures to enhance the reliability and validity of the study. The chapter concludes with a discussion of procedures utilized during data analysis.

#### **3.2 Research question, main aim and sub-aims**

##### **3.2.1 Research question:**

What was the effect of training in Problem Orientation and Definition (POD) on parents' orientation to and definition of problems experienced in parenting young children with moderate to severe communication disabilities?

##### **3.2.2 Main aim**

To investigate the effect of training in Problem Orientation and Definition (POD) on parents' orientation to and definition of problems experienced in parenting young children with moderate to severe communication disabilities.

##### **3.2.3 Sub-aims**

3.2.3.1 To develop and implement a training programme to facilitate parents' orientation to and definition of problems experienced in parenting young children with moderate to severe communication disabilities.

3.2.3.2 To determine parents' orientation to problems experienced in parenting young children with moderate to severe communication disabilities, pre- and post-training.

3.2.3.3 To determine parents' definition of problems experienced in parenting young children with moderate to severe communication disabilities, pre- and post- training.

### 3.3. Research design

A quasi-experimental, non-equivalent groups pre-test-post-test control group design was selected to determine the effect of the POD training programme on parents' orientation to problems (Dependent variable 1 [DV1]) and parents' definition of problems (Dependent variable 2 [DV2]). Field research with parents who had commitments regarding work, child care and family challenged the researcher's use of strategies to enhance internal validity (e.g. matching and randomization to control group assignment and ensure group equivalence) (McMillan & Schumacher, 2010; Cresswell, 2014). The selected design facilitated practice-based evidence because it catered for these challenges and provided reasonable control over many sources of invalidity (Bagnato, McLean, Macy, & Neisworth, 2011). Therefore, differences between the experimental and control groups' pre- and post-training scores on DV1 and DV2 could be attributed confidently to the training received (McMillan & Schumacher, 2010; Terre Blanche & Durrheim, 1999; Cresswell, 2014). Figure 3 illustrates the design's use in the current study.

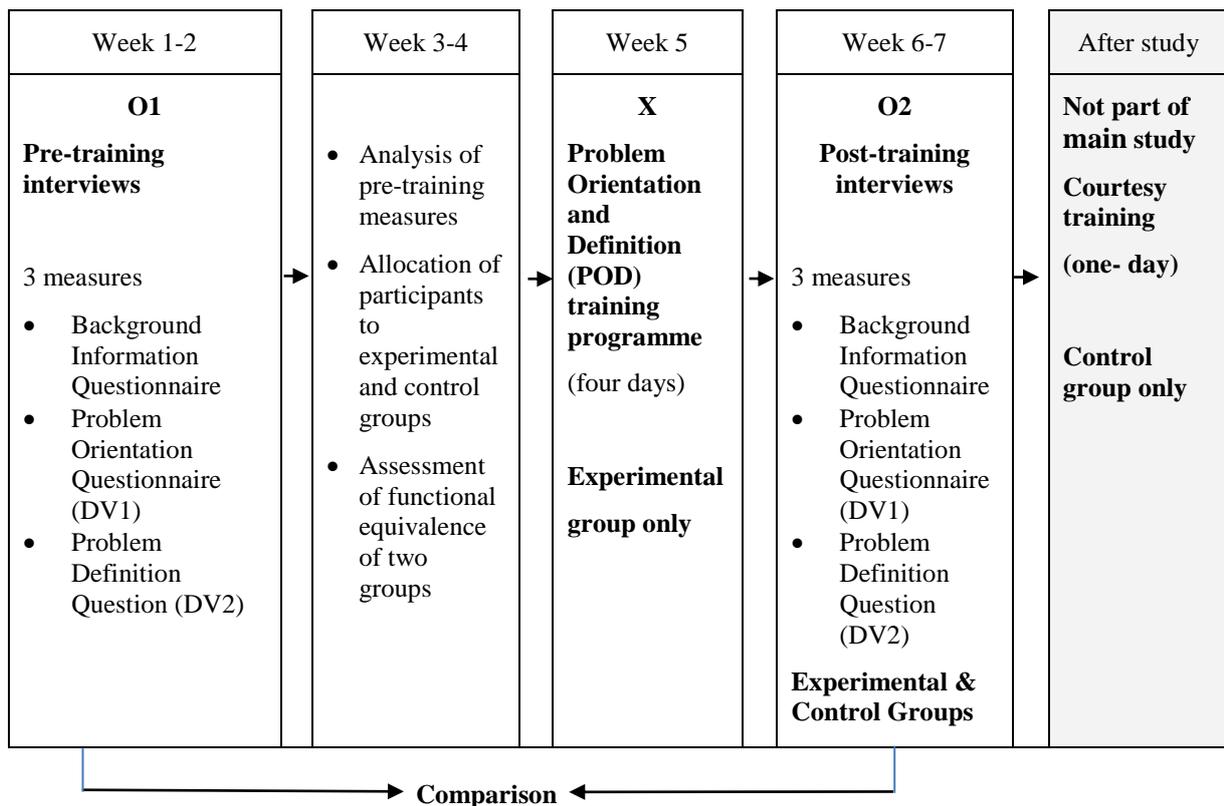


Figure 3: Schematic presentation of the research design

The pre-training interview schedule (comprising the Background Information Questionnaire, the Problem Orientation Questionnaire, and the Problem Definition Question),

were implemented with the experimental and control groups. Thereafter, the experimental group received the four-day POD training programme during the experimental phase, whilst the remaining group acted as a waiting control. One week after completion of the training programme, post-training interviews were conducted with parents from both groups. The same interview schedule was used in the pre- and post-training interviews to control for the effects of instrumentation (McMillan & Schumacher, 2010; Cresswell, 2014). In addition, both groups' exposure to the pre-training assessment eliminated bias introduced by pre-testing, and served to highlight any effects that the training had on the experimental group (all other conditions being equal). Other extraneous variables that were controlled to minimize threats to the study's outcomes, included: the selection of participants, instrumentation, subject attrition, diffusion of treatment, experimenter effects, participant effects (e.g. Hawthorne effect and time span between the pre- and post-interview) and statistical conclusions. Each variable is discussed in more detail as the chapter unfolds.

### **3.4 Research phases**

The study had two major phases, namely: (1) the pre-experimental phase and (2) the experimental phase. The phases are described in detail under 3.4.1 and 3.4.2 and are presented schematically in Figure 4.

#### **3.4.1 Pre-experimental Phase**

The three primary aims of the pre-experimental phase were: firstly, to develop and validate the pre- and post-training interview schedules that were used to determine (i) parents' orientation to problems they experienced, and (ii) parents' skills in defining these problems when accessing ECCI. Secondly, to develop and validate a training programme that would facilitate parents' use of positive problem orientation and definition skills; and thirdly, to ascertain the validity and reliability of the research design through a pilot study.

The development and validation processes used to achieve the three aims of the pre-experimental phase included: three pilot studies, three expert panel reviews, and two focus groups (one each with SLTs and parents). The panel reviews constituted the same experts throughout the validation process, thereby ensuring consistency in feedback for the three measuring instruments and training programme. To streamline the processes, information that was relevant within and across the three aims was sometimes gathered simultaneously.

For example, Expert review 2 and Pilot study 2 included all three instruments of the interview schedule at one time, whilst Pilot study 3 and the focus group with parents included information that was relevant for developing the schedules and training programme. However, the information is presented according to the three aims to facilitate understanding of the research process. Informed consent was obtained from all parents who participated in the pilot studies using forms that were adapted from those developed for the main study. All parents who participated in the pilot studies and focus groups were excluded from the main study. Figure 4 provides an overview of the processes followed in achieving each aim, whilst a discussion of each is presented in subsequent sections.

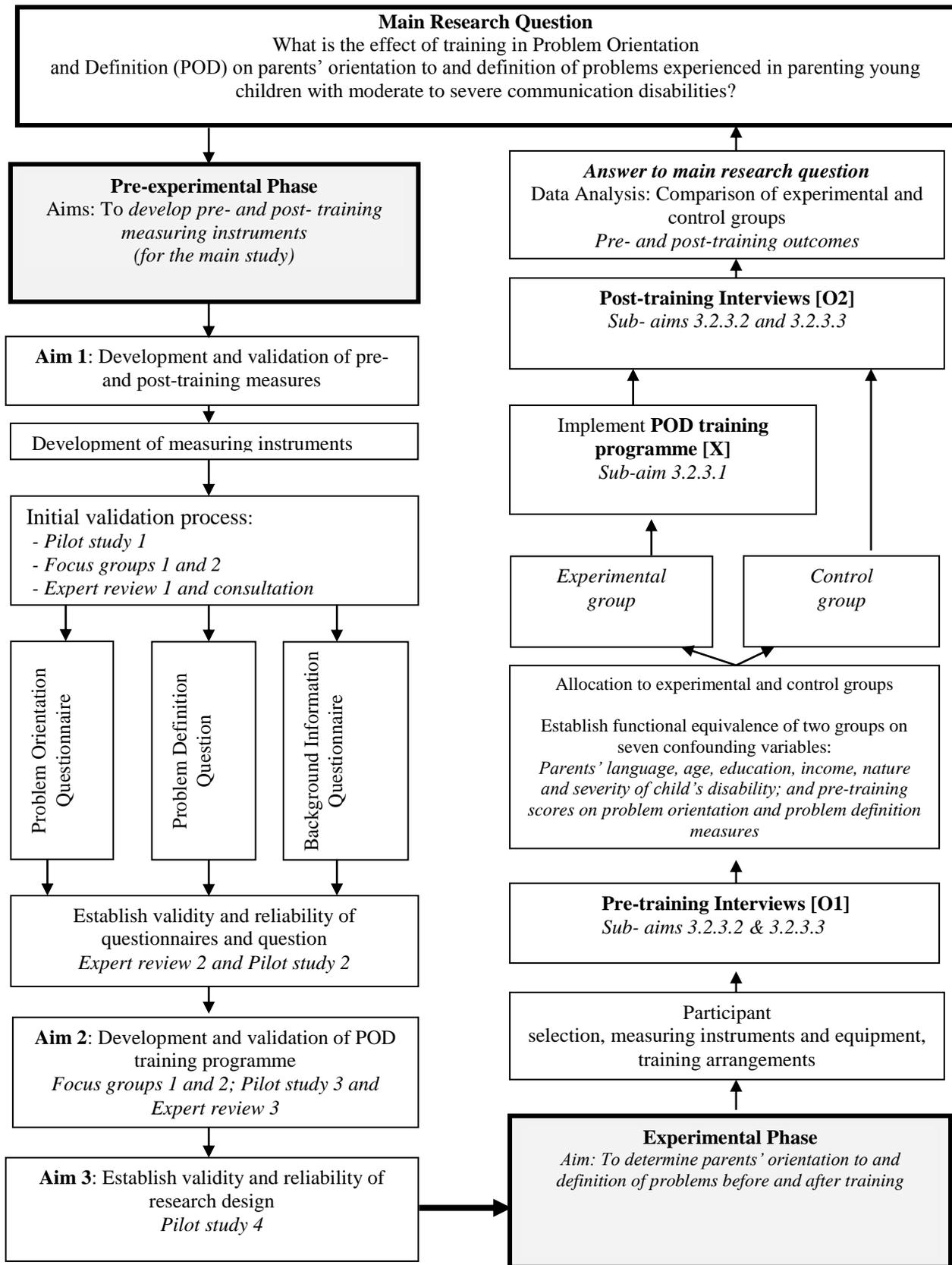


Figure 4. Schematic presentations of the Pre-experimental and Experimental phases

### **3.4.1.1 Aim 1: Development and validation of pre- and post- training interview schedules and questionnaires**

Validity and reliability were the critical factors that guided the development of the interview schedules to ensure that the instruments adequately and consistently measured the two theoretical constructs in the study, that is, parents' orientation to and definition of problems during ECCI in the pre- and post-training phases (Lynn, 1986; McMillan & Schumacher, 2001, 2010). Valid measures guaranteed that inferences and conclusions drawn from parents' numerical scores on the schedules were appropriate, meaningful and useful (McMillan & Schumacher, 2001, 2010; Bagnato, Neisworth & Munson, 1997). Reliability, on the other hand, ensured that on the two occasions of data collection, changes in parents' responses were confidently attributed to the effects of training (McMillan & Schumacher, 2001, 2010). Literature also highlights that the types of evidence selected must be consistent with the way in which results would be used (McMillan & Schumacher, 2001, 2010; Babbie & Mouton, 2001). Consultations with two statisticians indicated that evidence based on instrument content and response process was appropriate for the purposes of this study to strengthen intended interpretations and eliminate rival hypotheses.

The interview schedules comprised three measures: a Problem Orientation Questionnaire and a Problem Definition Question to assess DV1 and DV2, and a Background Information Questionnaire to provide the context for interpreting parents' responses. The pre-training and post-training schedules consisted of the same three measures to minimize variance due to instrumentation (McMillan & Schumacher, 2010; Cresswell, 2014). Since the schedules were developed locally for a specific context, it was important that a systematic method was employed to illustrate evidence of validity and reliability. The two-stage framework proposed by Armstrong, Cohen, Eriksen and Cleeland (2005); Lynn (1986) and Benson and Clark (1982) was used, which included a developmental stage and judgment-quantification stage.

The developmental stage consisted of four steps, namely (a) identifying the aim of the schedules; (b) conducting a literature review to identify content domains and dimensions for the constructs of problem orientation and problem definition, and identifying conceptual and operational definitions of each dimension included (already done in Sections 2.4.1 and 2.4.2); (c) identifying dimensions to evaluate parents' approach to and communication of problems during ECCI, using three methods: a pilot study, focus groups with SLTs and parents, and review and consultation with experts in the field; and finally (d) constructing the schedules.

The judgment-quantification stage entailed two steps: (a) assessment by experts to ensure that the items were representative of each dimension and construct, and that the content of the entire schedule was valid and reliable, and (b) administration of the pre-training schedule to parents through a second pilot study to establish content validity and reliability. The following sections discuss the stages during the development of the three measures that comprised the pre- and post-training interview schedules. Parents' dissatisfaction with intervention received during ECI provided the impetus for training parents to use positive problem orientation and definition behaviours when accessing ECCI (Dunst et al., 1988, 1994a; Dunst, 2004; Platt, 2008; Cegala et al., 2000; Fredrickson, 2002). The critical constructs of problem orientation and problem definition emanate from the theory of social problem-solving (D'Zurilla & Nezu, 1999; 2010), which provides a systematic method for assessing parents' approach to and communication of problems and needs during intervention, and identifies adaptive goals for training.

The social problem-solving literature reflected that many of the current problem-solving instruments focus on individuals' *appraisals* of their problem-solving skills rather than their actual problem-solving capacities, for example, The Problem-Solving Inventory (PSI; Heppner & Petersen, 1982); or assess individuals' general problem-solving skills, thus focusing broadly on all stages of the problem-solving process, for example, The Problem-Solving Self-Monitoring (PSSM) Form developed by D'Zurilla (1986). The PSSM Form, however, provided a relevant framework for assessing the constructs of problem orientation and problem definition (Appendix C), but it was not specific for parents' functioning within a communication assessment context. In addition, the language used was too complex for participants of this study. Therefore, measurement tools needed to be developed that met three criteria: (1) were specific to communication and the primary disability, (2) easily administered in busy public hospitals, and (3) easily understood by parents who were not first language English speakers and who had limited education. The theoretical frameworks proposed in Chapter 2 for understanding parents' orientation to and definition of problems during ECCI and the PSSM Form (D'Zurilla, 1986), were selected to guide the development of the Problem Orientation and Problem Definition measures. The proposed theoretical frameworks outline the content domains and the dimensions for the two constructs in a format that appeared appropriate for this study. However, prior to using both frameworks and the PSSM Form, a judgment stage was included by conducting three processes: a pilot study, two focus group discussions and an expert panel review to ascertain the relevance for parents accessing ECCI.

### 3.4.1.1.1 Initial judgment and validation stage

#### i) Pilot Study 1

**Aim:** To determine whether the content dimensions outlined for the problem orientation and problem definition domains in the proposed framework of problem orientation and definition for ECCI and the PSSM form were relevant for parents accessing ECCI.

**Participants:** Two parents of children with moderate to severe communication disabilities secondary to cerebral palsy, who received ECCI at a public hospital. Participants met all the inclusion criteria stipulated for the main study in point 3.4.2.1, and were judged by the resident SLT as coping well and able to communicate problems adequately. These criteria ensured that the two domains and respective dimensions were validated using parents who were regarded as ‘gold standards’ in the practice context. These parents were excluded from the main study. Both parents were mothers in the age range 30-40 years, who completed high school but did not work, since they took care of their children. The children were between the ages of 3 and 5 years.

**Procedure:** Exploratory, unstructured individual interviews were conducted at the parents’ homes in a quiet room, at a time suitable to the parents. The children were cared for by a family member. The researcher explained the purpose of the interview at the outset, and then asked parents to tell her about ‘the problems you experience in parenting your child with a communication disability and the help that you need from the speech therapist’. Interviews were audio-recorded and took an average of 35 minutes. Each interview was transcribed and analysed to ascertain (i) whether the content made reference, either directly or indirectly, to each of the five dimensions of the problem orientation domain, namely problem perception, causal attribution, problem appraisal, personal control and commitment and effort; and (ii) whether the two dimensions and sub-dimensions of the problem definition domain outlined in the framework facilitated the SLT’s understanding of the problem. The dimensions included (i) organization of information (with three sub-dimensions: ‘What is the problem?’, ‘Why is it a problem and what changes or additions are desired?’ and ‘What obstacle or obstacles prevented the parent from achieving the desired outcomes?’); and (ii) relevance of information (with sub-dimensions: ‘concrete’, ‘specific’ and ‘comprehensive’ with respect to the parent’s role in developing a meaningful and sustainable daily family routine).

**Results and recommendations:** All five dimensions of the problem orientation domain were generally reflected in the parents' descriptions. The two dimensions and sub-dimensions of the problem definition domain appeared very relevant in facilitating the SLT's understanding of the problem. The problem orientation and definition framework proposed in Chapter 2 and the PSSM Form were appropriate guidelines to use as the basis for developing the Problem Orientation Questionnaire and Problem Definition Question.

## **ii) Focus groups with SLTs and parents**

**Aims:** Focus group discussions with each stakeholder group were carried out to determine whether the five dimensions of problem orientation and two dimensions of problem definition (selected to measure the dependent variables), were indeed potential areas of concern for SLTs and parents during the collaborative problem-solving assessment process. These concerns could provide possible explanations for parents' dissatisfaction with intervention. Focus groups provided a convenient method to understand the perspectives of both participants with respect to the two domains, and ensured that the dimensions selected for the assessment and training process were valid (Babbie & Mouton, 2001; Bornman, Alant, & Lloyd, 2004; Cresswell, 2014).

**Selection of questions to facilitate discussion:** Literature pertaining to stress, coping and social problem-solving (refer to Chapter 2) was reviewed and a set of questions were identified per group. The questions were used to generate discussions about parents' orientation to and definition of problems during intervention, and the need for parent training. Since the questions were the primary tools for collecting data, the quality of the questions played a significant role in ensuring that the data were valid and reliable (Hill, Thompson & Williams, 1997). The questions were then presented to experts in the fields of ECCI (two SLTs) and problem-solving (two psychologists) to ascertain the relevance for achieving the aim of the focus group discussion and participants' ability to understand the questions and engage in relevant discussions. The four experts endorsed the validity and suitability of the questions for each stakeholder group.

**Participants:** Purposive sampling was used to select six participants for each of the two focus groups (Cresswell, 2014, Babbie & Mouton, 2001). Only one focus group per stakeholder group was utilized as the groups were homogenous. The following selection criteria were applied in each group: (i) SLTs were required to have two or more years of experience in treating children (0-6 years) with moderate to severe communication

disabilities, and work with parents/caregivers in a public hospital setting. This ensured that therapists had the necessary experience to make relevant contributions about the key variables of the study, namely parents' orientation to and definition of problems experienced in parenting their child under challenging socio-economic conditions. In addition, therapists had to volunteer to share their experiences and ideas about the topic. (ii) Parents were required to have a child (0-6 years) with a moderate to severe communication disability secondary to an established disability and who receives speech-language therapy at a public hospital. The latter constituted challenging circumstances and to manage them optimally, parents must approach and communicate their problems effectively when accessing help from SLTs. In addition, parents had to be able to speak and understand English at a level that facilitated their participation in the discussion (as assessed informally by the hospital SLT), and volunteer to participate in the focus group discussion.

Table 4 provides a summary of the procedure and results of the focus groups conducted with SLTs and parents, whilst Appendix D and Appendix F provide a detailed account of the procedure, analysis and results for each group respectively. The aim of the focus group was to determine whether the five dimensions of problem orientation and two dimensions of problem definition were identified as potential areas of concern when parents communicated problems to SLTs during assessment.

Table 4  
 Summary of focus groups with SLTs and parents

Procedure	Results	Recommendation
<p><b>Focus group 1</b></p> <p><b>Six SLTs</b></p> <p>Held at a local hospital's speech-language therapy department that was convenient for all.</p> <p>A research assistant audio-recorded the discussions.</p> <p>The researcher welcomed the group, outlined the purpose and used the list of questions in Appendix D to facilitate the discussion.</p>	<p>Information pertaining to the domains of problem orientation and problem definition are presented in order to ascertain the dimensions that therapists referred to:</p> <p><b>Problem orientation:</b> Therapists were generally able to gauge parents' beliefs, values and commitments (orientation) but did not have a structured method of evaluation. All agreed that parents' orientations were very important to assess, since it influenced positive outcomes during intervention. Therapists identified the following parent perceptions: difficulty accepting the disability or denial of disability, blaming themselves/medical staff, feelings of fear and not knowing what to do, lack of confidence in parenting skills, seeing the professional as the expert, willing to do anything to help their child.</p> <p>An analysis of these responses indicated that all 5 of the dimensions of problem orientation were included. Thus, the 5 dimensions were identified to be relevant. In addition, therapists supported the development of a systematic method of evaluating parents' orientations.</p> <p><b>Problem definition:</b> The majority felt that many parents did not communicate their problems adequately since concerns were generally described very broadly. Parent behaviours that hindered therapists' understanding of problems included limited knowledge of developmental milestones, disorganized descriptions, insufficient examples, difficulty communicating clearly, very little communication, not confident/comfortable talking to professionals. Parent behaviours that facilitated therapists' understanding of problems included coherent and organized descriptions, use of many examples from different contexts, good knowledge of developmental milestones and previous assessments, confident/comfortable when talking to professionals.</p> <p>Analysis indicates that therapists' responses make reference to the two dimensions selected to evaluate the domain of problem definition, namely organization of information and relevance of information. Thus, the two dimensions appeared relevant.</p>	<p>Include the 5 dimensions of the domain of problem orientation in the questionnaire to evaluate parents' orientation to problems experienced in parenting children with communication disabilities.</p> <p>Include the two dimensions of the domain of problem definition in the questionnaire to evaluate parents' definitions of problems experienced in parenting children with communication disabilities.</p>

Procedure	Results	Recommendation
<p><b>Focus group 2</b></p> <p>Six parents (all mothers).</p> <p>The procedure was the same as that outlined for Focus group 1.</p> <p>Description of parents:</p> <ul style="list-style-type: none"> <li>- Age range: 22 - 40 years</li> <li>- All took care of their children full-time (thus unemployed). The children were diagnosed with moderate to severe communication disabilities secondary to, for example, cerebral palsy; and they received ECCI at a public hospital.</li> <li>- Highest level of education ranged from grades 10 to 12.</li> <li>- Four were English first language speakers and two were English second language speakers, with their first language being isiZulu</li> </ul>	<p>Information pertaining to the domains of problem orientation and problem definition were presented in order to ascertain the dimensions that parents included:</p> <p>Problem orientation: Irrespective of the time post diagnosis of the child's disabilities, most parents experienced difficulties with coping. Parents indicated the following: feeling overwhelmed, fearful about the future and costs involved, unwilling to accept the diagnosis, wanting to seek a second opinion, felt that they were to blame, not sure what to do to help their child but willing to do anything, anxious/tense when talking to professionals—particularly those who were not English first language speakers, and those with limited education.</p> <p>Analysis revealed that the 5 dimensions of problem orientation were included in parents' responses. Thus, the 5 dimensions were relevant.</p> <p>Problem definition: Parents felt that they generally did not get all the help that they needed. They attributed this to their limited confidence in communicating their problems and needs to professionals as well as to professionals not listening to them. Their feelings of comfort with the professional affected the nature and amount of information that they shared. Some felt that professionals were busy people and parents therefore could not talk too much. Many felt that parents needed to state the child's communication difficulty (for example, 'she/he cannot talk properly') and how they felt she/he should be talking and that the therapist would then be able to help them.</p> <p>Analysis of parents' responses reflected a general lack of knowledge on how to define problems to professionals when seeking help. Thus, including the two dimensions of problem definition would be relevant to empirically ascertain parents' competence, and thereby guide parent training.</p>	<p>Include the 5 dimensions of the domain of problem orientation in the questionnaire to evaluate parents' orientation to problems they experienced in parenting children with communication disabilities.</p> <p>Include the two dimensions of the domain of problem definition to provide an empirical evaluation of parents' competence in defining problems they experienced in parenting children with communication disabilities.</p>

The findings of the two focus group discussions were positive and supported the relevance of the dimensions of problem orientation and problem definition for this study, as proposed by the theory of social problem-solving. To obtain further consensus on the dimensions and to determine whether the questions used in the PSSM Form, to assess the problem orientation and problem definition domains were appropriate for this study, a final review process involving experts in the field of ECCI was implemented.

### iii) Expert panel review 1

**Aim:** To determine whether the dimensions of the problem orientation and problem definition domains and questions assessing each in the PSSM Form, were appropriate for the aim of this study.

**Participants:** Seven qualified SLTs participated in the review. Therapists had between 6 and 30 years' experience in working with parents of young children with moderate to severe communication disabilities; they possessed postgraduate qualifications at doctoral level (1) or were pursuing doctoral studies in the field of ECI (6).

**Procedure:** Questionnaires were given to therapists, informing them about the purpose of the study, and aim of the review. They were also given a copy of the PSSM Form (only the sections pertaining to problem orientation and problem definition); and a summary of the theoretical framework proposed for parents' orientation to and definition of problems in ECCI. They were requested to rate the following, using a 4-point-rating scale: (a) the relevance of the dimensions and sub-dimensions of the problem orientation and problem definition domains as outlined in the theoretical framework for developing the measures and parent training programme; and (b) the relevance of the questions in the PSSM Form in both domains, for the aim of this study. The 4-point rating scale recommended by Lynn (1986) and Armstrong et al. (2005) was adapted and used as follows: 1 = not relevant; 2 = unable to assess relevance without item revision; 3 = relevant but needs alteration to suit the specific aim of the study; and 4 = very relevant.

**Results and recommendations:** All participants rated all dimensions of the problem orientation and problem definition domains as very relevant (4), but indicated that each needed to be adapted to suit the objectives of the current study. All questions assessing the domains of problem orientation and problem definition received a rating of 3 (i.e. relevant but needs revision) by all participants. For the domain of problem definition, participants indicated that asking parents to write down their problems might not be appropriate for the parent population targeted in this study, since there may be varying levels of literacy. It was recommended that all dimensions of the problem orientation and problem definition domains be included, but adapted to suit the aim and objectives of this study.

In summary, three processes were used to validate use of the basic theoretical framework proposed in Chapter 2 as well as the PSSM Form (D'Zurilla, 1986), as guidelines

to base the development of the problem orientation and problem definition measures. The results were largely positive, supporting the use of the two domains and respective dimensions and sub-dimensions to develop the two measuring instruments. Both were included in the pre- and post-interview schedules, in addition to the background information questionnaire.

The final stage in the development of the interview schedules was the construction of the three measures. The six standards of the LINK model of authentic curriculum-based assessment proposed by Bagnato, Neisworth and Munson (1997) provided the overall framework for the construction process, whilst specific guidelines by Benson and Clark (1982); Lynn (1986); and Armstrong et al. (2005) were also used. The six standards of the LINK model (namely; authenticity, convergence, collaboration, equity, sensitivity and congruence) integrates the processes of assessment-intervention evaluation and facilitates the use of “curriculum-based assessment of authentic, functional performance” (Bagnato et al., 1997, p. 41). Although the model was developed for use with young children, the six standards are very relevant and address the key challenge of developing a training programme of high quality that responds to parents’ needs with respect to orientation and definition of problems in ECCI. Information derived from the measures (assessment component) was used to formulate the goals and objectives of the training programme, select relevant training content and instructional strategies (intervention component); and to assess the outcome of training by using the same measures (evaluation component). The development of the Problem Orientation Questionnaire, Problem Definition Question, and Background Information Questionnaire is discussed next.

#### **3.4.1.1.2 Development and validation of the Problem Orientation Questionnaire**

The aim of the Problem Orientation Questionnaire was to determine parents’ orientation towards problems experienced in parenting young children with moderate to severe communication disabilities. The questionnaire comprised the five dimensions of the problem orientation domain. The questionnaire development process commenced with the adaptation of each dimension to suit the objectives of this study. Subsequently, content areas for each dimension were identified from the framework of problem orientation proposed in Section 2.3 (D’Zurilla & Nezu, 2010; Rossetti, 2001; Petersen & Steen, 2002; Peterson, Semmel, von Baeyer, Abrahamson, Metalsky & Seligman, 1982; Shonkoff & Meisels, 2000), in relation to the aim of the study. To identify relevant content areas for each dimension, the following question was posed: What information should the parent draw on in order to have a

positive orientation toward the child's communication disability, and other associated challenges?

Content areas for each dimension were identified and thereafter analysed to derive the underlying processes or parent reactions that the content evoked, for example, cognitive and affective processes such as parents' awareness, beliefs, values and feelings (Benson & Clark, 1982). Chapter 2 illustrated that, in this study, problem orientation reflected parents' perceptions of problems in general and disability in particular. These perceptions were derived from processes underlying parents' beliefs, values and commitments regarding: (i) the children's established and communication disabilities, (ii) parents' ability to use social problem-solving as a means to cope with the problems, and (iii) their past successes and failures in using independent problem-solving. Parents' cultural backgrounds and knowledge also played critical roles in influencing their beliefs, values and commitments regarding communication, disability, and independent problem-solving. The process of identifying parents' underlying reactions was important in order to develop appropriate objectives for the questionnaire, as well as for the training programme. Thus, the latter process guided the development of objectives for assessing each dimension. Table 5 captures the first stage of the questionnaire development process by outlining the five dimensions and adaptations made for ECCI, appropriate content areas selected for each, the corresponding process dimensions identified and culminates in the derivation of objectives for the questionnaire.

Table 5

*Development of the Problem Orientation Questionnaire*

<b>Dimensions of Problem Orientation for ECCI</b>	<b>Content areas</b>	<b>Process dimensions</b>	<b>Objectives of questionnaire</b>
1. Problem recognition  Parent's recognition/perception that the child's communication is a problem	- Typical development of communication - Significance of early identification of communication disabilities - Symptoms of a communication disability	- Beliefs about communication development - Value placed on communication skills	To assess parents' beliefs and values regarding communication and communication disabilities
2. Problem attribution  Parents' attribution of initial and maintaining cause/s of the child's communication	- Initial and maintaining causes of communication disability in children with established disabilities - Implications for parent's coping and intervention planning	- Beliefs regarding the causes of communication and established disability	To assess parents' beliefs regarding the causes of communication disability

Dimensions of Problem Orientation for ECCI	Content areas	Process dimensions	Objectives of questionnaire
disability			
3. Problem appraisal  Parents' evaluation of whether the child's communication disability and other associated factors represent potential harm or benefit to him/her (i.e. physically, psychologically, socially or economically)	<ul style="list-style-type: none"> <li>- The following are possible areas that influence parents' beliefs and perceptions of disability as a threat or challenge:               <ul style="list-style-type: none"> <li>- View disability from the medical rather than social model, thereby contributing to a negative view of child outcomes</li> <li>- View collaboration with professionals and the role of decision maker as challenges</li> <li>- View physical, socio-cultural and financial implications of raising a child with a disability, and the need for parent and family support, particularly for parents from low socio-economic contexts as challenges</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>- Beliefs regarding disability as a threat (harmful to the parent and family) or challenge</li> </ul>	To assess whether parents appraise disability and other associated factors as a threat or a challenge
4. Personal control  Parent's expectations regarding ECCI and its impact in ameliorating or resolving the child's communication disability and other associated challenges.  Parent's perception of his/her ability to help the child develop appropriate communication skills using his/her existing knowledge and skills  Parent's perception of his/her ability to help the child develop appropriate communication skills by accessing help from other people in the family and community	<ul style="list-style-type: none"> <li>- The following areas may underlie parents' expectations regarding ECCI and their ability to cope with raising a child with a communication disability:               <ul style="list-style-type: none"> <li>- The efficacy of ECCI</li> <li>- The importance of parents' positive functioning and its impact in facilitating positive outcomes in ECCI, particularly with respect to:                   <ul style="list-style-type: none"> <li>- Acknowledging/valuing the parent's role as decision maker</li> <li>- Acknowledging/valuing child/parent/family strengths (e.g. existing positive attitudes, knowledge and skills in parenting; the child's happy personality, the family having helpful neighbours, etc.)</li> <li>- Coping with cultural perceptions of disability</li> <li>- The need to be open to developing attitudes, knowledge and skills that can facilitate positive outcomes—for example, learning how to access</li> </ul> </li> </ul> </li> </ul>	Beliefs influencing expectations about: <ul style="list-style-type: none"> <li>- The efficacy of ECCI, and</li> <li>- Parents' ability to cope positively in parenting a child with a moderate to severe communication disability, in association with an established disability, under challenging socio-cultural and economic conditions</li> </ul>	To assess parents' beliefs regarding: <ul style="list-style-type: none"> <li>- the efficacy of ECCI, and</li> <li>- Their ability to cope positively in parenting the child with a moderate to severe communication disability, under challenging conditions</li> </ul>

Dimensions of Problem Orientation for ECCI	Content areas	Process dimensions	Objectives of questionnaire
	formal and informal support and resources (e.g. medical, education, financial and religious resources)		
5. Commitment of time and effort  Parent's understanding that the nature of the child's communication disability requires long-term commitment to ECCI to achieve positive outcomes  Parents' willingness to devote the time and effort required to assist the child in reaching his/her full potential through ECCI efforts	Parents understanding of the following areas are likely to influence their commitment of time and effort: - Chronic and long-term nature of challenges experienced by children with moderate to severe communication disabilities in association with established disabilities - The significance of active parent participation in intervention on a long-term basis, to facilitate positive outcomes for the child, parent and family - The role of ECCI in supporting parents and families with children from 0-6 years with disabilities, and the nature and availability of intervention services thereafter	- Parent's beliefs regarding the long-term nature of challenges experienced by children with moderate to severe communication disabilities, and the intervention available to support parents - Parents' ability to commit time and effort over a long period of time to enable the child to reach his/her full developmental potential	- To assess parents' beliefs regarding the long-term nature of challenges experienced by children with moderate to severe communication disabilities in association with established disabilities. - To assess parents' commitment ability over a long period of time to facilitate the child's ability to reach his/her full developmental potential

The second stage of questionnaire development identified relevant questions for each objective, appropriate response formats and developed guidelines for analysing and interpreting questionnaire scores. Firstly, the PSSM form, specifically Section A, questions a-h (D'Zurilla, 1986), the theoretical framework of problem orientation, the researcher's 22 years of experience in working with parents of children with moderate to severe communication disabilities, and findings from Pilot study 1 and the two focus groups were used to develop an initial set of 12 questions that met the objectives of the questionnaire. Guidelines by Babbie and Mouton (2001) were used to develop the questions. Only seven questions from the original PSSM form were included after adaptation (i.e. A3, B1, C1, D1, D3, E1, E2), whilst five new questions were included (i.e. A1, A2, B4, D5 and D6) (Appendix H). Closed-ended questions were used for all except two questions (B1 and B4), which were open-ended. Parents' responses to the two open-ended questions were rated according to provided closed-ended categories.

Secondly, careful attention was paid to the generation of response categories by using salient responses from Pilot study 1 and the focus group with parents. Both methods ensured that the categories captured the potential range of parents' responses accurately, in line with

the questionnaire's objectives. A four-point Likert scale was selected to obtain gradations of parents' beliefs, values and commitments regarding their children's communication and associated disabilities. The neutral choice was excluded, forcing respondents to reflect their orientation. The negative effect that it may have had on the accuracy of parents' responses was noted, but was deemed important for identifying areas for parent training purposes (McMillan & Schumacher, 2010).

Lastly, appropriate guidelines were developed to analyse and interpret parents' overall scores in the questionnaire (Appendix I). Details are presented in Section 3.4.2.5.

Two methods were implemented to establish validity and reliability of the Problem Orientation Questionnaire: (i) Expert panel review 2 (with the same participants as review 1), and (ii) Pilot study 2, with parents.

#### **(i) Expert panel review 2**

**Aims:** To determine whether the questionnaire development process reflected in Table 5 was appropriate, whether the 12 questions were relevant, logically sequenced and accurately represented the objectives of the questionnaire, and whether the questions were unbiased, unambiguous, clear and easy to understand for the target participants.

**Procedure:** The seven participants were presented with Table 5, to which an additional column was added outlining the questions for each objective. The criteria reflected for the three aims of the review were formulated into a brief questionnaire and participants were requested to provide a rating for each aim from 1 = appropriate to 4 = inappropriate, using guidelines adapted from Lynn (1986) and Armstrong et al. (2005).

**Results and Recommendations:** The participants provided positive responses on the questionnaire development process and the 12 selected questions. The question proposed for evaluating time and effort was identified as a double-barrelled question, and thus two questions were recommended. Minor editorial suggestions were made to simplify the formulation of all questions for the target population, for example, replacing the term 'communication' with 'talking'. The suggestions were implemented to ensure that the final 13 questions that were approved were easily understood by parents.

## (ii) Pilot study 2

**Aims:** To determine whether parents found the questionnaire instructions clear and easy to understand; whether the question and response categories were relevant, easily understood and appropriately sequenced and the time parents' took to complete the questionnaire

**Participants:** Two parents of children aged 3 and 5 years, who presented with moderate to severe communication disabilities secondary to autism and cerebral palsy. The parents were 28 and 35 years old, one completed high school whilst the other completed standard eight. Both parents cared for their children full-time. The parents were not included in the main study.

**Procedure:** Semi-structured individual interviews were conducted at the parents' homes in a context similar to Pilot study 1 and were audio-recorded. Parents were informed about the purpose of the study and encouraged to comment on the instructions, the relevance of the 13 questions, the adequacy of response categories and the ease of understanding both as well as any other aspect that they were not comfortable with. The questionnaire was printed in size 14 font, to facilitate the choice of response category.

**Results and recommendations:** The questionnaire took 8-10 minutes to complete, and parents found the instructions easy to follow. However, the following question and response categories posed difficulties: Firstly, for questions B1 and B2, one parent responded with 'I'm not sure', which was not included as a category. The category was therefore added. However, to maintain a four-point scale, the categories 'a problem in the parent' and 'a problem in the child' were combined, since both responses reflected internal attributions. In addition, analysis of the response categories for parent's attribution of initial and maintaining causes of the child's communication disability indicated that the information obtained from the questions was insufficient in determining whether the parent used a positive or negative attribution or explanatory style. The four response categories were appropriate as causal factors for communication disabilities, in contrast to other problems experienced in daily life. Thus, the information could not be used to infer whether parents' orientations were positive or negative for effective management of their child's communication disability. In order to increase the sensitivity of the measure by providing information about the parent's attribution style, two questions reflecting two dimensions of the concept of causal attribution were added with appropriate response categories. As discussed in Section 2.3.1.2, the internal versus external dimension was selected to determine the extent to which the parent blamed

herself/himself or other people or circumstances, whilst the stable versus unstable dimension was selected to ascertain the extent to which the parent perceived the initial cause to have a stable or unstable effect on the child's capacity to benefit from ECCI (Petersen & Steen, 2002). In both cases, the former reflected negative orientations, whilst the latter reflected positive orientations towards the child's communication disability.

The adapted questionnaire provided a composite measure of parents' orientations to problems, and contained five sections and 15 questions (2 open-ended and 13 closed-ended). Table 6 provides an overview of the questionnaire with respect to the five dimensions and respective sub-dimensions included, the objectives for each dimension and brief motivations reflecting how parents' responses meet the study's objectives. Detailed motivations are provided in Appendix H; Appendix J reflects the final questionnaire that was approved for the main study.

Table 6

*Overview of the Problem Orientation Questionnaire*

Construct dimensions	Objectives	Motivation
<b>A. Perception of communication problem</b> 2 Sub-dimensions: i. Recognition of communication disability (1 question) ii. Value placed on communication skills (2 questions) Total: 3 closed-ended questions (A1-3)	To assess parents' beliefs regarding communication disabilities and values regarding communication  Beliefs: 1 question Values: 2 questions	Parents' beliefs about typical communication development underlie their ability to recognize communication disabilities. Moreover, the value that parents place on communication skills will influence their decision to access communication intervention.
<b>B. Problem Attribution</b> 2 Sub-dimensions: i. Initial cause of the problem One open-ended question (B1) Two further sub-dimensions: - Internal versus external blame - Stable versus unstable nature of disability Two closed-ended questions (B2-3)  ii. maintaining cause of the problem One open-ended question (B4)	To assess parents' beliefs regarding the initial and maintaining causes of communication disability  Beliefs: 4 questions	Parents' explanatory or attribution style regarding the initial and maintaining causes will either facilitate or hinder their decision to seek and participate in ECCI. It is important for parents to accept the initial cause of the disability without self-blame, and to embrace the social model of disability when identifying maintaining causes. The latter in turn will facilitate relevant intervention planning and assist the child in reaching his/her full developmental potential.
<b>C. Problem Appraisal</b> 1 Dimension: i. Beliefs regarding disability as a threat or challenge: One closed-ended question (C1)	To assess parents' beliefs regarding disability as a threat or challenge  Beliefs: 1 question	Parents beliefs regarding the problems of parenting a child with a moderate to severe communication disability (e.g. financial, socio-cultural, time, effort, etc.), their role during intervention (e.g. role as decision maker, working with professionals), and the need for parent support (e.g. education and counselling, referral to other needed resources) are some of the factors parents mentioned in the focus group discussion, which influence whether parents perceive the disability negatively as a threat or positively as a challenge.
<b>D. Personal control:</b> 2 Sub-dimensions: i. Expectations regarding intervention outcomes ii. Expectations regarding parent's own ability to cope	To assess parents' beliefs regarding: i. The efficacy of ECCI and ii. Their ability to cope positively in parenting the child with a moderate to severe communication disability	Parents must believe that communication intervention will facilitate their child's ability to communicate needs, since this belief influences their intention to seek intervention. Moreover, parents must also

Construct dimensions	Objectives	Motivation
<p>with challenges: Four closed-ended questions (D1-4)</p> <p><b>E. Time and effort</b> 2 Sub-dimensions:</p> <p>i. Realistic estimation of time required to improve the child's communication</p> <p>ii. Willingness to devote time and effort to helping the child reach his/her full developmental potential: Three closed-ended questions: (E1-3)</p>	<p>under challenging conditions.</p> <p>Beliefs: 4 questions</p> <p>i. To assess parents' beliefs regarding the long-term nature of challenges experienced by children with moderate to severe communication disabilities, and the intervention available to support parents</p> <p>ii. To assess parents' commitment of time and effort over a long period to help their child reach his/her full developmental potential</p> <p>Beliefs: 1 question Commitment: 2 question</p>	<p>believe that they are capable of accessing as well as participating in intervention, in order to help their child communicate as best as she/he can.</p> <p>It is important that parents understand that ECCI is a long-term process with children who have moderate to severe communication disabilities in association with established disabilities. Thus, improvement may be slow and may occur in very small increments. In addition, it is important that parents are aware that their time and effort are critical during intervention to facilitate the child's communication development.</p>
<p><b>Total 15 questions</b> 13 closed-ended questions 2 open-ended questions</p>	<p><b>Underlying process:</b> Beliefs: 11 questions Values: 2 questions Commitment: 2 questions</p>	

### **3.4.1.1.3 Development and validation of the Problem Definition Question**

In Chapter 2, problem definition was operationally defined as the parent's ability to communicate in an organized manner and provide relevant information about the child's communication and/or other associated problems, in order for the professional to understand the problem. The latter, in turn, facilitated the collaborative decision-making process and culminated in the identification and selection of relevant intervention goals, methods and activities. In a two-stage process similar to that followed for the Problem Orientation Questionnaire, the development of the Problem Definition Question commenced with adapting each dimension of the problem definition construct to suit the objectives of this study. Table 7 outlines the first stage of the question development process, where content areas, underlying processes, and the objectives of the question were identified.

Table 7  
*Development of the Problem Definition Question*

<b>Dimensions of problem definition relevant for ECCI</b>	<b>Content areas</b>	<b>Process dimensions</b>	<b>Objectives of question</b>
1. Organization of information presented in an organized and coherent manner facilitates the therapist's understanding of the problem	Information that is easily understood is organized and presented logically according to the three components proposed by D'Zurilla & Nezu (1999; 2010) - adapted for the study as: - What is the problem, to whom is it a problem and why? - What changes or additions are desired, by whom and why? - What obstacle/s prevent/s the desired outcome/s?	Skill in communicating about the child's communication difficulties and/or other associated problems in a logically organized manner	To assess the parent's skill in communicating in an organized, coherent manner about the child's communication problem/s, and/or other associated problems
2. Relevance of information and the parent's interpretations thereof (behaviours and events) clarify the nature of the problem, so that appropriate intervention goals are planned.	Information in each of the three components listed above must be relevant, that is: - Relate to the parent's or family's functioning in their respective roles of creating a sustainable, meaningful daily routine, and relate to the wider physical, financial and socio-cultural environment—if applicable. - Be concrete or operationalized within the family's daily life routine by providing examples, be described in relation to the parent's role, using familiar terms; and - Be comprehensive in containing all available facts and parent perceptions that are specific to the child's communication or other associated problems	Skill in identifying relevant information about the child's communication difficulties and/or other associated problems	To assess the parent's skill in identifying relevant information about the child's communication problem/s, and/or other associated problems

Table 1 provides an overview of the relevant information required in the three components.

The second stage of question development comprised three aims: (i) developing question/s that enabled parents to demonstrate their skill in communicating relevant information about the problem in an organized, logical manner that facilitated the SLT's understanding of the problem; (ii) developing a rating scale to measure parents' skills in these two dimensions of problem definition; and (iii) developing guidelines to analyse and interpret parents' final score in the measure.

**Development of the open-ended question:** One open-ended question was developed to fit in with the case history component of ECCI. Probe questions were used to obtain clarification of information only (e.g. unintelligible utterances) and not to direct the parent to areas/topics that were not described adequately. The single question was used pre- and post-training.

**Development of the rating scale for problem definition:** Four-point rating scales were developed to measure the two dimensions and respective sub-dimensions of the problem definition domain. The two dimensions were considered equally important in facilitating professionals' understanding of problems, and were thus weighted equally. Similarly, the respective sub-dimensions were also weighted equally in relation to each other. The nature of the information that should be contained in each dimension and sub-dimension for definitions to be easily understood by the SLT, is outlined in Table 1 and was supported in the initial validation processes (Pilot study 1, Focus groups 1 and 2 and Expert review 2). A data capturing and rating sheet was developed to facilitate the rating process. Finally, guidelines to analyse and interpret parents' overall problem definition score were also developed, and are discussed later in Section 3.4.2.5.

Because the process that was followed was the same as that implemented for the Problem Orientation Questionnaire, only aspects specific to the Problem Definition Question are discussed. Two methods were used to establish validity and reliability of the Problem Definition Question: (i) Expert panel review 2 (with the same participants as in Expert review 1), and (ii) Pilot study 2.

### **(i) Expert panel review 2**

**Aims:** The aims were to determine whether the question development process as reflected in Table 3.4 was appropriate; whether the one open-ended question was unbiased, unambiguous, clear and easy to understand for the target participants and allowed for appropriate demonstration of skills in problem definition; and whether the methods selected for evaluating and interpreting parents' skills in problem definition were relevant (i.e. rating scale, data capturing and rating sheet, as well as analysis and interpretation guidelines).

**Procedure:** The seven participants were presented with the content of Table 7, the problem definition question and rating scales, data capturing and rating sheet, and the guidelines for analysis and interpretation. The criteria reflected for the three aims of the review were formulated into a brief questionnaire and participants were requested to provide a rating for

each aim from 1 – appropriate to 4 – inappropriate, using guidelines adapted from Lynn (1986) and Armstrong et al. (2005).

**Results and recommendations:** The participants' responses were generally positive with respect to the question development process. Minor editorial changes were suggested to simplify the question for the target population. The removal of the initial words 'I'd like you to ...', and the replacement of the word 'communication' with the word 'talking' (similar to the problem orientation questionnaire). Minor linguistic changes were also suggested to improve the clarity of the rating scales and the guidelines for analysis and interpretation. All suggestions were implemented.

## **(ii) Pilot study 2**

**Aims:** To determine the following: (i) whether the open-ended question was relevant and easily understood by parents from the target population; (ii) whether the rating scales, data capturing and rating sheet, and guidelines for analysis and interpretation were appropriate for evaluating parents' skills in the two dimensions of problem definition; and (iii) the time taken to complete the interview and rating procedure.

**Participants:** The two parents who assessed the Problem Orientation Questionnaire were also requested to assess the Problem Definition Question.

**Procedure:** Semi-structured interviews were implemented, similar to those followed for the Problem Orientation Questionnaire. Parents were asked to comment on the clarity and ease of understanding the open-ended question and on any other aspect that they were not comfortable with. After the interviews, the researcher listened to the audio-recordings of the interviews, transcribed the interviews, and then used the transcript to capture, rate, analyse and interpret parents' problem definitions using the rating scales, data capture and rating sheet, and the analysis and interpretation guidelines developed for the study.

**Results and recommendations:** The interview took between 6-10 minutes to complete, and both parents found the question easy to follow. Each interview was transcribed in 20 minutes. Problems encountered with the rating scale included the need for greater clarity between the categories: good organization and moderately good organization for Dimension 1. The same applied for the categories relating to the sub-dimensions of specificity and comprehensiveness in Dimension 2. In addition, the format of the rating scale required minor

revision to facilitate the rating process. The rating process took 10 minutes per participant. The process also indicated that relevant information from the audio recording could be captured directly onto the data capture and rating sheet, thus eliminating interview transcription and saving time. Minor editorial revisions were suggested for the analysis and interpretation guidelines. All recommendations were implemented.

Table 3.5 provides an overview of the revised question and measurement methods developed to evaluate parents' definition of problems. Final versions of the problem definition question and rating scales, data capture and rating sheet, and guidelines for the analysis and interpretation are provided in Appendix K, Appendix L and Appendix M respectively. The open-ended question was formulated as:

“Please tell me about the difficulties you have with your child’s talking, and what help you would like from the speech therapist. I have not seen your hospital file and therefore don’t know anything about you or your child. Give me all the information that *you think I should know*, in order for me to understand your difficulties and help you.” Probe questions were used to obtain clarification of information only (e.g. unintelligible utterances) and not to direct the parent to areas/topics that were not described adequately.

Table 8

*Overview of question and process to measure parent’s skills in problem definition*

Dimensions of problem definition	Method of measurement
<p><b>Dimension 1 : Organization of information</b> to facilitate understanding:            Three sub-dimensions:</p> <ul style="list-style-type: none"> <li>- What is the problem, to whom is it a problem and why?</li> <li>- What changes/additions are desired, to whom and why?</li> <li>- What obstacles prevent the achievement of desired outcomes?</li> </ul>	<ul style="list-style-type: none"> <li>- A 4-point rating scale was developed with 4 = good organization, facilitating very good understanding of problems, to 1 = poor organization, resulting in poor understanding of problems.</li> <li>- Each sub-dimension was rated and then added to obtain a composite score for Dimension 1 (organization of information).</li> </ul>
<p><b>Dimension 2 : Relevance of information</b>            Three sub-dimensions:</p> <ul style="list-style-type: none"> <li>- Specificity of information to the problem</li> <li>- Use of concrete/operational terms</li> <li>- Comprehensiveness of descriptions</li> </ul>	<ul style="list-style-type: none"> <li>- A 4-point rating scale was developed to evaluate the relevance of information (Dimension 2) provided in each of the sub-dimensions of Dimension 1 (organization of information) listed above. Relevance of information was ascertained by evaluating the sub-dimensions of specificity, concreteness and comprehensiveness of information.</li> <li>- Ratings for the sub-dimensions of specificity, concreteness and comprehensiveness of information ranged from 4 = good, to 1 = poor.</li> <li>- A composite score for each sub-dimension of relevance was obtained. Thereafter, the scores of the three sub-dimensions were added and an average reflected a composite score for relevance of information.</li> </ul>

<b>Dimensions of problem definition</b>	<b>Method of measurement</b>
<b>Calculation of problem definition skill score:</b>	
<ul style="list-style-type: none"> <li>- The two dimensions of problem definition were considered equally important to facilitate the SLT's understanding of the problem, and thus weighted equally.</li> <li>- An average of the final scores in both dimensions provided an overall final composite score referred to as the Problem Definition Skills Score.</li> <li>- A scale was developed to interpret the parent's problem definition skills score in line with the study's objectives, and is discussed in the data analysis section in Section 3.4.2.5.</li> </ul>	

#### **3.4.1.1.4 Development of the Background Information Questionnaire**

The aim of the Background Information Questionnaire was to collect relevant biographical information for each parent in order to provide a context for interpreting their orientations to and definitions of problems experienced in parenting children with moderate to severe communication disabilities (i.e. DV1 and DV2), as measured in the pre- and post-training interview schedules. Four types of information were deemed important to facilitate meaningful interpretations of parents' responses on the dependent variables, namely, (1) information on the parent/caregiver; (2) information on the family; (3) information on the child; and (4) information from the SLT's evaluation of the child and parent. Twenty-six closed-ended questions were initially developed.

The process that was followed was similar to that used for the Problem Orientation Questionnaire and Definition Question. The two methods used were: (i) Expert panel review 3 (with the same participants as in Expert panel review 1), and (ii) Pilot study 2.

##### **(i) Expert panel review 2:**

**Aims:** To determine whether the questions in the Background Information Questionnaire were: (i) appropriate for the aim of the study, (ii) worded clearly and within the capability of the target participants to understand and answer, and (iii) logically sequenced.

**Participants:** The same participants were used as in the Expert panel review 1.

**Procedure:** The seven participants were given a draft of the questionnaire containing the 26 questions and asked to comment on the aims above, in the provided questionnaire.

**Results and recommendations:** The reviewers found the questionnaire was too comprehensive and recommended the removal of four questions that were not directly applicable to the aim of the study. The remaining 22 questions were considered appropriate, logically sequenced and within the capability of parents and SLTs to answer. Minor editorial

corrections were suggested to improve the clarity of questions. All recommendations were implemented.

## **(ii) Pilot study 2**

**Aims:** To determine the following: (i) whether the instructions and questions were clear and easily understood by parents and SLTs, (ii) whether both participants were capable of answering all questions asked and (iii) the time taken to complete the questionnaire by both participants.

**Participants:** The two parents who assessed the Problem Orientation Questionnaire and the Problem Definition Question, and their respective SLTs.

**Procedure:** Semi-structured interviews - similar to those followed for the Problem Orientation Questionnaire and Problem Definition Question. Speech-language therapists were requested to provide information on the child's established disability and nature and severity of communication disability. Both participants were asked to comment on the clarity and ease of understanding the questions, their ability to provide the information required, and any other aspect that they were not comfortable with.

**Results and recommendations:** The interviews took approximately 5 minutes to complete; both parents and SLTs found the questions clear and were able to provide the information with ease. No modifications were required.

Table 9 provides an overview of the Biographical Information Questionnaire. The four categories of information, the nature of questions posed and brief motivations for each category of information are outlined. For a detailed discussion of the development of the biographical information questionnaire, refer to Appendix N. The final questionnaire approved for the main study is included in Appendix O.

Table 9

*Overview of Biographical Information Questionnaire*

Category	Questionnaire area	Motivation
<b>General interview information</b> Four closed-ended questions	Parent identification number Experimental /Control group Pre-training/Post-training interview Referral source (institution) Participant: mother/father	This section contained general administrative information and identified whether the mother or father was the participant.
<b>Part 1: Background information on the parent/caregiver</b> One open-ended and 7 closed-ended questions	Contact details Age First language and race Highest level of education Employment Marital status Physical health Mental health	The demographic variables listed may influence parent's orientations to and skills in defining problems experienced in parenting children with moderate to severe communication disabilities.
<b>Part 2: Background information on the family</b> One closed-ended question	Total family income per month	This study targeted parents from low-income backgrounds who accessed intervention at public hospitals. Parents in this group faced tremendous challenges in parenting young children with disabilities, and needed to use positive problem-solving skills.
<b>Part 3: Background information on the child</b> One open-ended and 2 closed-ended questions	<ul style="list-style-type: none"> <li>- Name</li> <li>- Age</li> <li>- Primary medical diagnosis (Established risk factor)</li> </ul>	Parents of children 0-6 years with moderate to severe communication disabilities in association with established disabilities were selected for the study, since the children presented greater challenges to parenting. It was therefore critical that parents showed positive problem orientations and were skilled in problem definition in order to facilitate positive outcomes for the child and family.
<b>Part 4: Speech-language therapy summary profile of:</b> - child's communication disability - parent's health and coping  <b>5 closed-ended questions</b>  <b>Total: 21 questions</b>	Developmental domains: <ul style="list-style-type: none"> <li>• Cognitive skills</li> <li>• Motor skills</li> <li>• Communication skills               <ul style="list-style-type: none"> <li>- Receptive language</li> <li>- Expressive language</li> <li>- Social/pragmatic skills</li> </ul> </li> </ul> <ul style="list-style-type: none"> <li>- Speech-language therapist's estimate of severity of the child's overall disability</li> <li>- Speech-language therapist's informal assessment of parent's physical and mental health, and coping.</li> </ul>	The study focused on children with moderate to severe communication disabilities, secondary to established disabilities, since parenting is a challenge experience (Singer & Irvin, 1989; Rossetti, 2001).  Parenting children with moderate to severe disabilities may have a significant effect on parents' physical and mental health, with consequent impact on their orientation to and definition of problems (Rossetti, 2001). Therapists' informal assessment of parents' coping and functioning would highlight the need for parent support programmes as part of ECCI (Dunst, 2004).

Table 10 provides a final analysis of the three measures with respect to the six standards of the LINK model (Bagnato et al., 1997; Bagnato et al., 2010), which ensured that there was integration of the assessment-intervention processes.

Table 10

*Overview and analysis of measures according to six LINK standards*

<b>Six LINK Standards</b>	<b>Problem Orientation Questionnaire</b>	<b>Problem Definition Questionnaire</b>	<b>Biographical Information Questionnaire</b>
<b>Authenticity</b> Do the measures focus on actual parent perceptions and skills in the intervention context?	The five dimensions relate to actual parent perceptions during ECCI	The two dimensions relate to actual parent communication behaviours that facilitate or hinder parents' skills in problem definition	Not applicable
<b>Convergence</b> Is there more than one source of information?	Parent and SLT	Parent and SLT	Parent and SLT
<b>Collaboration</b> Do the measures require cooperation and sharing between parents and professionals?	Assessment requires cooperation between parent and SLT		
<b>Equity</b> Do the measures accommodate rather than penalize parents' special needs (e.g. cultural, education, linguistic)?	Measures were developed to accommodate the majority of parents from low socio-economic backgrounds with respect to education, language and cultural status		
<b>Sensitivity</b> Are there sufficient items to plan training and detect changes in perceptions and skills?	Fifteen questions Yes	Yes. One open-ended question evaluated according to two dimensions of the construct of problem definition	Twenty-one questions Yes
<b>Congruence</b> Are the measures developed and field - tested with parents similar to the target population?	Focus group and pilot studies used parents from similar target population		

In summary, the first aim of the pre-experimental phase was achieved with the development and validation of the three measures that comprised the pre- and post-training interview schedules. Significant reliability issues were also addressed, including participant fatigue and maintaining motivation by ensuring that the interview schedules could be completed within an hour and at one sitting (McMillan & Schumacher, 2001). Finally, Appendix P provides an overview of sections and questions in the pre- and post-training interview schedules that were expected and not expected to remain consistent. The next section discusses the second aim of the pre-experimental phase, namely, development and validation of the POD training programme.

### 3.4.1.2 Aim 2: Development and validation of POD Training Programme

Development and validation of the training programme followed a similar process to that of the measuring instruments. Literature on the design and implementation of quality parent training programmes, especially for parents from diverse backgrounds, were reviewed (Dunst et al., 1989; Slater, Martinez & Habersang, 1989; Neef & Parish, 1989; Bagnato et al., 1997; Dunst & Trivette, 2009; Montgomery & Schubart, 2009; Saunders, Evans, & Joshi, 2009; Schwarzer, 1999, 2001; Conn, 2009a; Conn, 2009b; Bryan, Kreuter, & Brownson, 2009; Finfgeld, 2004; Cortes, Mulvaney-Day, Fortuna, Reinfeld & Alegrõa, 2009; Helitzer, Peterson, Thompson & Fluder, 2008; Hill, 2011); in addition to the parent intervention studies evaluated in Sections 2.3.1 and 2.3.2 (i.e. Hawkins & Singer, 1989; Davis & Rushton, 1991; Pelchat et al., 1999; Morrison et al., 2003; Barnett et al., 2003; Herbst & Maree, 2006; Greenfield et al., 1985; Anderson et al., 1987; Thompson et al, 1990; Frederickson & Bull, 1995; McCann & Weinman, 1996; Cegala et al., 2000; Alegría, Polo, Gao, Santana, Rothstein, Jimenez, et al., 2008; Woods & Lindeman, 2008; Hill, 2011). The review of parent intervention studies identified minimal research on interventions that supported parents' orientation to *and* definition or communication of their problems and needs to professionals during help seeking. Individually, the studies were limited regarding provision of a framework that addressed four issues that were considered crucial for intervention planning in this study: (i) integrating training in problem orientation and definition in the context of parents seeking help in ECCI; (ii) adopting the overall theoretical tenets of capacity building and family-centred intervention as proposed by Dunst (2004); (iii) initiating and sustaining changes in parents' beliefs about disability and help seeking, and their communication behaviours in this regard; and (iv) utilizing teaching and learning philosophies and methods that aligned with the study's main theoretical tenets. Consequently, an evidence-based training framework was derived by identifying and integrating training philosophies and practices from the studies reviewed, to address the four issues outlined. The following guidelines were selected to develop and implement the training programme to facilitate parents' orientation to and definition of problems in ECCI: aim of the training programme; training philosophy, training content; training structure and process; training environment, and evaluation strategy (Singer & Irvin, 1989; D'Zurilla & Nezu, 2010; Hill, 2011). The application of the guidelines in the study are discussed and summarized in Table 11.

The **training aims** were guided by the theoretical framework of problem orientation and definition proposed in Section 2.3, and the study's overall goal. The aims were authentic, since they were derived from focus group discussions with parents and SLTs (Section 3.4.1.1.1) (Bagnato et al., 1997; Bagnato, 2007; Dunst, 2004).

The **training content** was derived through an analysis of parents' role as help seeker/s during ECCI, i.e. consumer and decision-maker (Granlund et al., 2005); and the proposed theoretical framework of problem orientation and definition in Section 2.4. The authentic curriculum-based approach (Bagnato et al., 1997; Bagnato, 2007; Bricker & Cripe, 1992) was used to identify parent competencies with respect to problem orientation and definition (i.e. values, knowledge and skills), and thereby the relevant content for training. The content areas that were specified in the development of the problem orientation and definition measures in Tables 5 and 7, were applicable and therefore included for the training programme.

The **training philosophy** was derived from different sources to create a context that aligned with the study's core aim to empower, inspire and nurture parents' beliefs, values and skills that were vital for competent help seeking and decision-making during ECCI (Finfgeld, 2004; Dunst 2004; Granlund et al., 2005). Firstly, the study's global theoretical context, namely parents' positive functioning as embedded in Dunst's (2004) integrated framework of ECI and family support, presented key principles, i.e. a) parent support through capacity building using family-centred help giving practices constituted the broad theoretical basis for training (Dunst, 2004; Dunst et al, 2002), and b) principles of promotion, empowerment, recognizing parents' strengths and utilizing their individual and community resources guided training at all levels.

Secondly, the **training structure and process** operationalized mechanisms for changing parents' problem orientation and definition capacities as proposed in Table 1, Section 2.4; and in line with the core principles outlined. The overriding principle from the outset was that the training structure and implementation process were realistic in terms of outcomes, feasible for use with culturally diverse parents from low socioeconomic backgrounds, and cost-effective for professionals working in busy hospital environments where time and finances were limited (Montgomery & Schubart, 2009; Zinkin & McConachie, 1995; Dunst, et al., 1994a; NPC, 2011). To ensure that therapists and parents

used the programme, it had to be simple for both groups to understand and employ (Bricker & Cripe, 1992; Dunst & Trivette, 2009).

Training was structured in four phases that addressed core elements of the change process from an individual and environmental perspective, to promote parents' positive orientations (beliefs, values and commitments) and skills in problem definition. The phases were derived from the Health Action Process Approach (HAPA) (Schwarzer, 1999; Schwarzer & Renner, 2000) and supported with the five key factors of change management proposed by Crookes (1998). The four phases commenced with motivation and goal setting, and proceeded to initiating and maintaining perceptual and behaviour changes, and concluded by evaluating the design, implementation and outcome of training (Schwarzer, 1999). Careful attention was given to the five factors that mediated positive training outcomes (Crookes, 1998): attributes of parents and their social, economic, educational and linguistic environments (discussed in Section 2.3.1.1); attributes of the theoretical framework of problem orientation and definition underpinning training (proposed in Table 1, Section 2.3); competence of the trainer (discussed later in Section 3.4.2.4.1); and the training philosophy and methods selected to initiate and sustain the change process. The four phases are discussed in more detail in Section 3.4.1.2.1.

The training process focused on two issues that the intervention literature highlighted, to initiate and sustain positive changes in parents' orientation to and definition of problems, i.e. establishing an enabling, empowering, collaborative, problem-solving parent-professional partnership; and conceptualizing teaching and learning as a mutual process between parent and professional (Tannen & Wallet, 1986; Anderson et al., 1987; Björck-Åkesson, Granlund, & Simeonsson 2000; Dunst, 2004; Dunst & Trivette, 2009). Parent-professional partnership was guided by theoretical principles from family-centred intervention (Dunst, 2004; Björck-Åkesson et al., 2000; Dunst et al., 2002; Granlund et al., 2005), value-based partnership with oppressed groups (Nelson, Prilleltensky & MacGillivray, 2001); parent empowerment (Björck-Åkesson et al., 1996; Dunst et al., 1994b; Finfgeld, 2004; Cortes, Mulvaney-Day, Fortuna, Reinfeld & Algefiá, 2009), and collaborative problem-solving (Björck-Åkesson et al., 1996; Granlund et al., 2005; D'Zurilla & Nezu, 1999; 2010). The principles supported the establishment of an open, power-sharing, trusting and respectful communicative interaction between parents and the trainer to ensure that parents felt comfortable to discuss personal and sensitive issues about their problems and needs in parenting children with moderate to severe communication disabilities—and to communicate with SLTs. Collaborative decision-making,

parents' choice, voice and control, and the valued expertise and strengths of both partners in creating workable solutions for parenting problems were emphasized as the basis of the relationship. Studies reviewed illustrated that the trainers' values, knowledge, interpersonal and facilitation skills (e.g. listening, empathizing, understanding, and respectful communication) were critical in developing the desired relationship with parents (Nelson et al., 2001; Tannen & Wallerstein, 1986; Anderson et al., 1987; Finfgeld, 2004).

The teaching and learning process incorporated principles from evidence-based approaches that included the Participatory Adults Learning Strategy (PALS) (Dunst & Trivette, 2009); social cognitive theory (Bandura, 2001); constructivism and experiential learning (Sawyer, 2006; Kolb & Kolb, 2005); parent adaptation and positive functioning (Barnett et al., 2003); and the authentic curriculum-based approach (Bagnato et al., 1997; Bagnato, 2007; Bricker & Cripe, 1992). The principles that underpinned training included: teaching and learning as an individual and social process, parent motivation and self efficacy as important mediators of learning, parents' prior knowledge and experiences as the basis for constructing and facilitating positive orientations and communication behaviours, and the use of adult learning strategies that were relevant for parents who had varied coping skills and came from diverse socioeconomic and education backgrounds. Training targeted parents' beliefs, perceptions, thoughts, emotional reactions and communication skills to facilitate problem orientations and definitions that enhanced help seeking during ECCI (Barnett et al., 2003; D'Zurilla & Nezu, 1999; 2010). Training strategies that initiated positive shifts in parents' perspectives about their problems and their ability to manage them were crucial, in view of the positive effect of including problem orientation in problem-solving training (Houts, Nezu, Nezu, & Bucher, 1996; Nezu, 2004; D'Zurilla & Nezu, 1999; 2010), and the short four-day duration of training.

Didactic training methods were used to provide parents with specific information about the help seeking and help giving process in ECCI, the significance of collaborative problem-solving, and the relevance of parents' social problem-solving behaviours (specifically problem orientation and definition) in achieving positive outcomes. Parent and trainer mediated training methods (e.g. guided reflection) were used to facilitate or strengthen the use of positive problem orientation and definition skills. Appendix Q presents details of the theoretical principles that underpinned the overall training philosophy, including parent-professional partnership and the teaching and learning process. A description of the training methods that were used is also included, for example, hand-outs, role play, trainer guided reflection and analysis of case studies and parent's stories, personalized feedback,

inspirational slideshows, informal learning contexts during refreshment breaks, and three videos of parents who displayed effective and ineffective help seeking behaviours (Bricker & Cripe, 1992; Dunst & Trivette, 2009; Bryan et al., 2009; Sawyer, 2006). Figure Q1 provides a schematic presentation of the training philosophy and methods. Appendix R describes the development and validation of the POD hand-out, Appendix S provides the final hand-out that was approved, and Appendix T outlines the development and validation of the three POD videos. A training plan was developed using the key components from the framework of problem orientation and definition proposed in Section 2.3, and the outline in Tables 5 and 7. Appendix U provides a detailed description of the training plan and outlines specific competencies for the two dependent variables as well as the targeted learning domains, the aims, training content, training methods, equipment, and evaluation strategies that were implemented for each competency. In contrast to patient communication intervention studies reviewed in Table 3 (Section 2.3.2), training was sequenced to focus first on facilitating parents' positive orientations towards children's established and communication disabilities and help seeking from ECCI professionals; and to subsequently promote effective problem definition skills when communicating problems and needs to professionals. The training sequence was important for two reasons: (i) social problem-solving theory (D'Zurilla & Nezu, 1999; 2010; Nezu, 2004) emphasized the partial independence of the processes of problem orientation and problem-solving, and research highlighted the significant effects of training outcomes when problem orientation was included (Nezu & Perri, 1989; Nezu, 2004; Houts et al., 1996)

A **training venue** was secured at a public hospital that was easily accessible to parents. The venue was designed for in-service training of hospital staff. It was situated in a quiet area and equipped with the resources required for training purposes (e.g. tables and chairs; whiteboard for writing; electronic facilities for using teaching resources, such as power-point presentations and a separate space for serving refreshments).

**Process and outcome measures** were developed to evaluate the training programme. Process measures were important to ensure that training occurred as planned, and problems were identified and corrected as required. These measures ascertained whether and how the training process occurred, parents' experiences of training at the end of each day, fidelity to the training plan and theoretical framework, and the trainer's reflections on the training process at the end of each training day (Forgatch, Patterson & DeGarmo, 2005). Outcome measures utilized the Problem Orientation Questionnaire in Appendix J, and Problem Definition Question in Appendix K to evaluate whether parents' problem orientation and

definition behaviours had changed following training (Helitzer et al., 2008; Saunders et al., 2009).

Table 11 summarizes the guidelines and its application in developing the training programme.

Table 11

*Training guidelines and application in developing the training programme*

Training guidelines	Application in developing training programme
<p><b>Training aims</b></p> <ul style="list-style-type: none"> <li>• Specific to the study's two dependent variables</li> <li>DV1: Problem orientation</li> <li>DV2: Problem definition</li> </ul>	<ul style="list-style-type: none"> <li>- To facilitate parents' use of positive orientations (beliefs, values and commitments) that initiate and maintain help seeking from ECCI, when confronting challenges associated with parenting young children with moderate to severe communication disabilities.</li> <li>- To facilitate parents' skills in providing relevant information in an organized manner when defining problems to SLTs.</li> </ul>
<p><b>Overall philosophy</b></p> <ul style="list-style-type: none"> <li>• Health promotion and positive functioning (Dunst, 2004; Snyder &amp; Lopez, 2002)</li> <li>• Family-centred intervention (Dunst, 2004)</li> <li>• Value-Based Partnership (Nelson et al., 2001)</li> <li>• Enabling and empowering relationship (Dunst et al., 1994b; Dunst, 2004; Dunst &amp; Trivette, 2009; Finfgeld, 2004; Cortes et al., 2009)</li> <li>• Collaborative problem-solving (Björk-Åkesson et al., 1996; Granlund et al., 2005)</li> </ul>	<p>Core values as applied in the study's context:</p> <ul style="list-style-type: none"> <li>- Health promotion and positive functioning: Adopted a systems level intervention that focused on competency building and the endorsement of healthy attitudes and behaviours that protect and enhance parents' positive functioning, and thereby that of the child and family</li> <li>- Family-centred intervention: Intervention was responsive to parent/s' identified concerns and needs, recognized strengths, and facilitated access to resources; acknowledged unique expertise of parents' knowledge of the problematic situation and professionals' knowledge and skills in ECCI, to identify solutions that were most likely to resolve identified problems.</li> <li>- Caring, compassion and community: An attitude of caring and compassion between the partners to foster mutual trust. From the professional's perspective, placed the agenda of completing the study in line with parents' needs, and helped parents feel safe, accepted and comfortable to express their honest opinions.</li> <li>- Human diversity: to value and respect partners' cultural, linguistic and economic diversity, which contributed to their unique identities.</li> <li>- Social justice: ensured <b>parents' access</b> to the following resources: relevant information, practical and emotional support, skills development; and <b>professionals' access</b> to information regarding challenges experienced in parenting young children with moderate to severe communication disabilities, secondary to established disabilities; and needs that professionals could assist with.</li> <li>- Empowerment, participation, self determination and power-sharing: encapsulated in giving parents control during training through having a voice and choice.</li> </ul>
<p><b>Training content</b></p> <ul style="list-style-type: none"> <li>• Derived from the parent's role as help seeker during ECCI, namely consumer and decision-maker (Granlund et al., 2005)</li> <li>• Used an authentic curriculum-based approach (Bagnato et al., 1997; Bricker &amp; Cripe, 1992) to identify required competencies of parents' in the role of help seeker in ECCI (Granlund,</li> </ul>	<ul style="list-style-type: none"> <li>-Positive problem orientations (i.e. problem recognition, attribution, personal control, commitment of time and effort and appraisal) and effective problem definition skills (i.e. communicating specific, concrete and comprehensive information in an organized format to professionals during ECCI) were identified for parents' roles as consumer and decision-maker during ECCI.</li> <li>- The underlying processes of parents' orientations to and definitions of problems (namely, beliefs, values, commitments and skills) were identified and targeted as training objectives. The objectives related to having positive beliefs, values and commitment regarding children's moderate to severe communication disabilities secondary to established disabilities, and approaching professionals for help; and skills in presenting relevant information in an organized manner. That is, competence in the role of</li> </ul>

Training guidelines	Application in developing training programme
2005)	help-seeker during ECCI.  - Parents' orientation to problems and skills in problem definition were evaluated before training in order to tailor training content to meet their specific needs.

### Training structure

- Health Action Process Approach (Schwarzer, 1999; 2001)
  - A training plan was developed and training was structured in 4 phases:
  - Phase 1: Motivation & Goal Setting Phase
  - Phase 2-3: Volitional Phase (initiating and maintaining changes in parents' orientation and problem definition skills, and managing relapses)
  - Phase 4: Evaluation of Training (evaluating planning, content, implementation)
- Social validation of training plan (Lewis et al., 1991; Anderson, et al., 1987; Kulukulualani (2008)
  - A three-step participatory process was implemented to validate the need for training, relevance of the intended aims, structure, instructional methods, and evaluation of training outcomes. First, two focus groups (one with SLTs and the other with parents of children with moderate to severe communication disabilities). Second, a review by clinical experts in the field of ECCI, and third; a pilot study with two parents of children with moderate to severe communication disabilities.

### Training Process

*Trainer focused on two key aspects:*

#### (i) Parent-professional relationship building:

- Enabling and empowering parent-trainer interactions
- Sensitive to learners' culture, language, economic and education backgrounds

#### (ii) Teaching and learning process:

- Mutual teaching and learning process
- Adult learning principles (Dunst & Trivette, 2009)
- The change process and parents' adaptation (Schwarzer, 1999; Cortes et al., 2009; Barnett et al., 2003; Bandura, 2001)
- Use of cost effective teaching resources

(Dunst & Trivette, 2009; Montgomery & Schubart, 2009; Bryan et al., 2009; Finfgeld, 2004; Cortes et al.,

- A systems/ecological approach was adopted through focus group consultations with parents and professionals at pre-training to ensure responsiveness to parents' needs (Sameroff & Fiese, 2000).

- The trainer adopted a critical role in facilitating parent-professional relationship. The following roles were adopted: *consultant* (embraced a problem-solving approach, facilitated desired problem orientations and definition behaviours; acknowledged not having all the answers; mutual teaching and learning between parent and trainer); *diagnostician* (integrated information from the pre-test and training session evaluations of parents beliefs, values, commitments and skills, and made meaningful decisions regarding training); *educator/coach* (observed parents' feelings, thoughts towards problems and their problem definition behaviours, understood parents' leaning styles, paid attention to parents' responses and the internal dialogue that it portrayed, and tailored training to maximize parents' strengths while reducing hindrances) (Kendall, 1991; Nelson et al., 2001; Dunst & Trivette, 2009).

- Teaching strategies were practical and suitable for the intended sample of parents' learning styles. Teaching resources were easy for professionals at public hospitals to access and use.

- Parents' cognitive, emotional, social and behavioural attributes were targeted to initiate and sustain positive changes in their feelings, behaviour and thinking (Barnett et al., 2003).

- Follow-up assistance to sustain the change process included homework assignments; easy access to the trainer; and contact with SLTs based at clinics and hospitals in the community (Saunders et al., 2009).

Training guidelines	Application in developing training programme
2009; Woods & Lindeman, 2008; Alegría et al., 2009)	
<b>Training environment</b> Feasible in a hospital/clinic setting	- Training facilities at a public hospital.
<b>Evaluation of training</b> <ul style="list-style-type: none"> <li>• Process and outcome evaluations (before, during and after training) (Saunders et al., 2009; Helitzer et al., 2008)</li> </ul>	<ul style="list-style-type: none"> <li>- Pre-training and post-training interview schedules</li> <li>- Parent’s evaluations: (i) after each training session, (ii) general evaluation at the end of training</li> <li>- Integrity of training programme rating form</li> <li>- Trainer’s reflection notes after each training day</li> </ul>

A brief overview of the four training phases is provided.

#### 3.4.1.2.1 Overview of training phases:

**Phase one** centred on *strengthening parents’ motivation* to engage in the training process by focusing on their perceptions of the child’s disabilities, the demands placed on parenting, their crucial role as change agents and decision-makers in the lives of their children and families, equal partnership between parents and professionals during collaborative problem-solving when accessing ECCI, relevance of parents’ problem-solving and help seeking skills in managing their daily challenges effectively (Granlund et al, 2005; McConkey, 1995; Singer & Irvin, 1989; Bryan et al., 2009), and the benefits of problem orientation and definition training in enhancing parents’ help seeking and problem-solving skills in general. Enabling and empowering parents to internalize their critical role as change agents and advocates in the child and families’ lives was central (Rossetti, 2001; Dunst et al., 1994a; Dunst, 2004). Instructional methods included: personal stories and group discussions of parents’ experiences; slideshows, case study and a video to inspire and promote change in perspective (e.g. video illustrating an individual who chose to be positive in embracing severe physical disability); information sharing on the significance of help seeking to manage parenting demands, particularly the parent’s roles as consumer and decision-maker; and finally, the critical importance of parents’ beliefs about their own learning capabilities (self-efficacy) in order to maximize training benefits (Dunst & Trivette, 2009; Bandura, 2001).

**Phase two** focused on *initiating perceptual and behaviour changes* in parents’ problem orientations and problem definitions. Parents’ perceptions of problems were targeted first, followed by problem definition behaviours, as changes in behaviour are

predicated on changes in participants' awareness and attitudes (Peter, 1992). Training included information on problems being a normal part of life for *all* individuals, thus requiring individuals to possess relevant knowledge, attitudes and skills to manage problems effectively (a key point emphasized throughout training); the importance of emotions in facilitating recognition of problems; and the role that each dimension of problem orientation played in promoting parents' positive coping and functioning (i.e. problem perception, causal attributions, problem appraisal, personal control in terms of outcome expectancies and self-efficacy; and commitment of time and effort). Training methods utilized observation, analysis and reflection as critical processes to promote perceptual and behaviour change through case studies of and presentations by mothers who adopted the role of 'warrior mums' in managing life's challenges (e.g. life-threatening illnesses; children's severe disability), lectures explaining the five dimensions of problem orientation, videos depicting parents of children with disabilities who embraced positive orientations towards problems encountered, and power-point slideshows that illustrated relevant inspiring messages that facilitated cognitive re-framing, POD handout and homework assignments that included writing in a personal diary (Dunst & Trivette, 2009; Le Cornu, 2009; Barnett et al., 2003; Davis & Rushton, 1991; Kendell, 1991; Bryan et al., 2009; Cegala et al., 2000; McCann & Weinman, 1996; Kaptein & Lyons, 2009; Willig, 2009).

The use of effective problem definition skills during help seeking in ECCI followed, namely, providing relevant information in an organized manner by following the three-step framework proposed in Section 2.3.2 (i.e., what is the problem, to whom and why; what changes are desired, by whom and why; and what obstacles prevent the achievement of desired outcomes?). The identification of 'relevant information' (i.e., specific, concrete and comprehensive), and communicating this information in a way that is easily understood by the help giver (in this case, SLT) was stressed, in order to access the help needed. Teaching methods were similar to those already listed, and included lectures, video material depicting parents using effective and ineffective problem definition skills, role-playing and constructive feedback, the POD hand-out and homework assignments (Dunst & Trivette, 2009; Greenfield et al., 1985; Anderson et al., 1987; Thompson et al., 1990; Frederickson & Bull, 1995; McCann & Weinman, 1996; Cegala et al., 2000).

**Phase three** focused on *maintaining perceptual and behaviour changes* in parents' problem orientations and problem definition through planned follow-up services. Three methods were planned to ensure that systems were created to facilitate parents' use of preferred competencies, namely (1) homework assignments given at each session to initiate

the maintenance programme (e.g. gratitude journal); (2) providing the trainer's contact details to facilitate participants easy access during the training period; and (3) setting up follow-up services with the child's SLT at the hospital context to promote continued parent support after completion of the study. Therapists would be seen in a group context after the study and presented with an overview of the training objectives, programme content and training strategies, and advised on how they could strengthen and maintain the desired competencies. The trainer's continued role as consultant would be emphasized to ensure that hospital therapists received the support they required in order to maintain training efforts (Dunst & Trivette, 2009).

**Phase four** focused on *evaluating the design, implementation and outcome of the training* programme, using relevant process and outcome measures (Helitzer et al., 2008; Saunders et al., 2009; Dunst & Trivette, 2009). Firstly, the trainer's adherence to the intervention's core content components and competent execution of clinical and teaching practices during training were evaluated by one of the research assistants using the integrity of training programme rating form (Appendix Y). Parents' experience of the training sessions were also evaluated daily, using the training session evaluation form (Appendix V) Secondly, the effectiveness of the training programme in facilitating parents' use of positive orientations to problems and effective skills in problem definition were evaluated through the pre- and post-training interview schedules. Thirdly, the extent to which the training programme met parents' needs as identified in the focus group, were evaluated using the pre- and post-training interview schedules as well as the general evaluation questionnaire in Appendix W (which assessed the entire study). Lastly, factors internal or external to training that facilitated or inhibited the impact of the programme were evaluated to guide the planning of future training initiatives in similar contexts. The evaluation was conducted through the general evaluation questionnaire and the evaluation form for the training session.

#### **3.4.1.2.2 Social validation of the training programme**

Three methods were used to evaluate the social validity of the training programme: (i) focus groups with SLTs and parents, (ii) Expert panel review 3 (with the same participants as in Reviews 1 and 2), and (iii) Pilot study 3 (with the same two parents who assessed the questionnaires and question in Pilot study 2).

**Aims:** To determine the need for parent training in problem orientation and definition during ECCI, to ascertain whether SLTs should provide the training, to assess the face and

content validity of the POD training hand-out and three videos that were specifically developed for the study, and to determine whether the overall planned training programme met the six LINK standards.

**Focus groups with SLTs and parents:** The two focus groups evaluated whether it was worthwhile and valuable for SLTs to train parents to be competent help-seekers by facilitating positive problem orientation and definition behaviours. Findings indicated that both groups of participants strongly supported the need for training. Speech-language therapists felt that the training could be implemented by any early intervention professional, and that SLTs were especially important in view of their expertise in communication (Hentz & Ellis, 2010). Parents indicated that although they received varied levels of support from rehabilitation professionals at the hospitals, none of the support focused specifically on strengthening their help seeking skills—thus highlighting the dire need for parent training in problem orientation and definition to access the help that they needed. Although most parents indicated that they would attend training if it were provided, some cited limited child-care support as a challenge.

**Expert panel review 3:** Table 11, drafts of the detailed training plan, the two measures of problem orientation and problem definition, the three evaluation forms, the training hand-out, scripts of the three training videos, and the six LINK standards were presented to the seven reviewers in an online discussion forum. They were asked to use the six LINK standards to evaluate the relevance and congruence of the training aims, structure and content and instructional strategies with the two measures and the three evaluation forms (i.e. training session evaluation form [Appendix V], integrity of training rating form [Appendix Y], and the general training evaluation form [Appendix W]). Appendix Z illustrates the review form used to assess congruence between the training plan and measures of problem orientation and problem definition, to ensure social validation of the training programme. Therapists' responses were very positive and findings indicated that the six LINK standards were met. Feedback related to modifying the depth of the training content while not affecting its impact (specifically relating to the sub-dimensions of problem perception and causal attribution) so that it could be easily implemented by therapists practicing in hospital contexts, integrating questions on the general evaluation form to decrease repetition, and minor editorial corrections on the training session form and integrity of training programme rating sheet. The review and feedback on the training hand-out and

training videos are described in detail in Appendices R and T. All recommendations were implemented.

**Pilot study 3:** The main aim was for SLTs and parents to assess the suitability of the training hand-out and videos as instructional materials that would facilitate parents' use of positive problem orientation and problem definition skills during ECCI. The participants were the same two parents and their respective SLTs, who participated in Pilot study 2. The findings were positive and are described in detail in Appendices R and T. All recommendations were implemented.

In summary, the second aim of the pre-experimental stage was completed with the development and validation of the POD training programme. The final aim in the pre-experimental phase required establishing the validity and reliability of the entire study design to identify and resolve any aspects that may compromise the findings in the main study, and to address the challenge of ascertaining whether the training content and process were sufficiently strong to facilitate changes in the dependent variables. Thus, Pilot study 4 was conducted to enhance the internal validity of the study design.

### **3.4.1.3 Aim 3: Determining validity and reliability of the research design**

Pilot study 4 established the validity and reliability of the overall research design.

#### **3.4.1.3.1 Objectives of Pilot study 4**

The objectives of the pilot study were to evaluate the applicability of the entire research process, including pre- and post-training interview schedules, the training programme, data capturing, scoring and analysis procedures. Specific objectives are presented in detail in Appendix AA.

#### **3.4.1.3.2 Context and participants**

The pilot study was conducted at a public hospital in the eThekweni District in Kwa-Zulu Natal, South Africa. This training site was selected as it compared favourably with the training conditions outlined for the main study (i.e., a public hospital in the same district). Permission to conduct the study at the hospital was obtained from the Kwa-Zulu Natal Department of Health, the hospital chief executive officer, and the resident SLT. Participant selection criteria as well as recruitment strategies were the same as that of the main study (identified later). Informed consent was obtained from the four participants who were

recruited by the resident SLT; however, only two participants attended. The two participants who did not attend were unable to make alternate care-giving arrangements for their children. The pilot study was therefore implemented with two participants. Table 12 outlines the demographic profile of the participants.

Table 12

*Background information of participants in Pilot Study 4*

Category	Participant 1	Participant 2
<b>Background information of the participant</b>		
<b>Relationship to the child</b>	Mother	Mother
<b>Age</b>	30 years	26 years
<b>Highest educational qualification</b>	High school (not completed)	High school (completed)
<b>First Language</b>	English	English
<b>Marital status</b>	Married	Married
<b>Occupation</b>	Housewife	Housewife
<b>Total family income for the month</b>	R2100 – R3000	R4000
<b>Participant's health (as described by parent)</b>	Not good (receiving treatment for depression)	Excellent
<b>Background information of the child</b>		
<b>Gender</b>	Male	Male
<b>Established risk factor</b>	Cerebral palsy	Autism
<b>Age</b>	6 yrs	3years 2 months
<b>General health</b>	Satisfactory	Good
<b>Speech-language therapy summary profile</b> (provided by the child's SLT)		
<b>Rating of child's general developmental skills:</b>		
Cognitive skills	Age inappropriate	Age inappropriate
Motor skills	Age inappropriate	Age appropriate
Receptive language	Age inappropriate	Age inappropriate
Expressive language	Age inappropriate	Age inappropriate
Pragmatic/social skills	Age inappropriate	Age inappropriate
<b>Severity of communication disability</b>	severe	Moderate to severe

### 3.4.1.3.3 Procedure

- The recruitment process was similar to that of the main study (refer to Section 3.4.2). The therapist emailed the contact details of the four participants to the researcher.

- The researcher contacted each participant, thanked them for volunteering, reinforced the benefits of participation for the parent, and made arrangements for participating in the pilot study. The two participants who were able to participate consented to the video and audio-recordings of the pre- and post-training interviews and training programme. They also indicated a preference to have both interviews at their homes, and to have the training done in three days over two weeks.
- Pre- and post-training interviews and the training programme were implemented by the researcher.
- Training was presented over three days for a total period of 10 hours. For pilot study purposes, this was deemed sufficient, especially in view of training two participants only. If training proved to be minimally beneficial to the parents, it would strengthen the need for pursuing the full duration of training. On Day 1, training occurred between 13h00 and 17h00, and Days 2 and 3 from 9h00-12h00 to accommodate parents' care-giving arrangements.
- The detailed training plan outlined in Appendix U was followed, but adapted for use over three days. Key training methods were targeted to establish relevance in facilitating positive changes in parents' problem orientation and definition.
- The researcher and three trained external raters assessed procedural and measurement reliability of the pre- and post-training interviews and training programme, to ensure that the reliability measures and process were relevant for the main study. Descriptions of the raters, their training, and the assessment of procedural and measurement reliability are provided in the main study in Section 3.4.2.3
- Participants evaluated the three-day training sessions using the training session evaluation form at the end of each day (Appendix V), and the general evaluation questionnaire at the end of the entire programme (Appendix W).
- Table 13 summarizes the pilot study design and training schedule.

Table 13

*Summary of the design and implementation of Pilot Study 4*

<b>Training day</b>	<b>Design</b>	<b>Procedures</b>
<b>Day 1</b>	<b>O1</b>	<ul style="list-style-type: none"> <li>- The researcher did the pre-training interviews with participants at their homes.</li> <li>- Interviews were video and audio recorded.</li> </ul>
<b>Day 2-3</b>		<ul style="list-style-type: none"> <li>- Transcription of two pre-training interviews</li> <li>- Preliminary analysis of participants' performances in DV1 (Problem orientation) and DV2 (Problem definition) in order to tailor the training programme to fit participants' needs. For DV1, the dimensions of problem attribution, personal control and problem appraisal required specific attention; in addition to both dimensions of DV2 (i.e. organization and relevance of information).</li> </ul>
<b>Day 4</b>  4 hours	<b>X</b>	<p>Commenced with training - Day 1</p> <p><b>Session 1:</b> Introduction and motivation – phase 1- 90 minutes</p> <ul style="list-style-type: none"> <li>- Overview of help-seeking, problem orientation and problem definition</li> <li>- Parents' stories</li> <li>- Problem orientation (phase 2): five dimensions</li> </ul> <p>Training methods: lecture with power-point slides, group discussion, cognitive reframing</p> <ul style="list-style-type: none"> <li>- <b>Tea break:</b> 30 minutes</li> </ul> <p><b>Session 2:</b> exposure to positive orientations –105 minutes (short 3 minute breaks in-between)</p> <ul style="list-style-type: none"> <li>- Video – “Are you going to finish strong?”</li> <li>- Story of ‘warrior mum’</li> <li>- Key issues on the five dimensions of problem orientation that facilitate positive functioning (e.g. communication skills, transactional model of causation, etc.)</li> <li>- ECCI and parent involvement</li> </ul> <p>Training methods: modelling, case study, small group discussions, cognitive restructuring, hand-outs, guided reflection</p> <p><b>Conclusion:</b> 15minutes</p> <ul style="list-style-type: none"> <li>- Summary of training for the day</li> <li>- Homework assignment: gratitude journal</li> <li>- Training session evaluation (Appendix V)</li> <li>- Assistant rating of integrity of training sessions(Appendix Y)</li> </ul>
<b>Day 9</b>  3 hours	<b>X</b>	<p>Commenced with training: Day 2</p> <p><b>Session 1:</b> 90 minutes</p> <ul style="list-style-type: none"> <li>- Overview of problem orientation training and summary of key learning points</li> <li>- Problem definition (phase 2) – two dimensions</li> <li>- role of parent and SLT during assessment</li> <li>- Video 1 and discussion</li> <li>- <b>Tea break:</b> 30 minutes</li> </ul> <p><b>Session 2:</b> 50 minutes</p> <ul style="list-style-type: none"> <li>- Problem definition (phase 2) continued</li> <li>- Videos 2 and 3 – evaluation and discussion using hand-out</li> </ul> <p>Training methods: hand-out; lecture; group discussion, guided reflection, cognitive restructuring</p> <p><b>Conclusion:</b> 10 minutes</p> <ul style="list-style-type: none"> <li>- Summary of training for the day</li> <li>- Homework assignment: use the handout guidelines to practice communicating problems and needs to the SLT. Prepare for individual presentations on Day 3.</li> <li>- Training session evaluation(Appendix V)</li> <li>- Assistant rating of integrity of training sessions(Appendix Y)</li> </ul>

Training day	Design	Procedures
Day 10 3 hours	X	Commenced with training: Day 3 <b>Session 1:</b> 90 minutes - Overview of problem definition training and summary of key learning points - Parent presentations of problem definition - Review and evaluation of presentations - Summarize and consolidate key principles of problem orientation and problem definition - <b>Tea-break:</b> 30 minutes <b>Session 2:</b> Final review and consolidation – 45 minutes - Review and discussion of homework assignment given on day 1 – gratitude journal - Open session: to answer any queries that parents have about the training provided. Reinforce the concept of parent as decision-maker, change-agent and ‘warrior mum’ - PowerPoint slide-show: “We are like pencils” Training methods: individual practice presentations; constructive feedback; PowerPoint slideshow; problem-solving group discussions, hand-out. <b>Conclusion:</b> 15 minutes - Training session evaluation (Appendix V) - General evaluation of entire training programme (Appendix W) - Certificate of attendance (Appendix X) - Assistant rating of integrity of training sessions (Appendix Y) - Discuss arrangements for post-training interviews
Day 12	O2	- The researcher did the post-training interviews with participants at their homes. - Interviews were video and audio recorded, and transcribed.

#### 3.4.1.3.4 Objectives, results and recommendations of Pilot study 4

Table 14 provides a summary of the key objectives, results and recommendations, while Appendix AA provides further details. The six LINK standards were used to guide analysis.

Table 14

*Summary of objectives, results and recommendations of Pilot Study 4*

Objectives	Results and recommendations
The following were assessed for the pre- and post-training interview schedules: (i) Parents’ understanding of instructions and questions (ii) recording of parents’ responses (iii) sequencing of measures (iv) time taken to complete both schedules (v) interview environment in facilitating good quality recordings (vi) Data capturing, scoring	- Overall findings according to the six standards were generally positive. - Minor editorial errors were noted and corrections recommended with respect to questions in the problem orientation questionnaire to facilitate parents’ understanding. - Recording of parents’ responses presented minimal problems. - Problems were encountered with the sequence in which the problem orientation and definition measures were implemented. Recommended presenting the Problem definition question before the Problem orientation questionnaire in the main study. - Pre-training interviews were completed in 45-60 minutes, whilst post-training interviews took 15-20 minutes. - Parents’ home environments were generally adequate and did not pose a serious threat to the quality of video and audio recordings. - Data capturing and analysis: The raters did experience some problems with the rating process—requiring further attention to training. For this study, video recordings of interviews did not prove to be superior to audio recordings for rating purposes. In addition, ratings using transcriptions of interviews and audio

Objectives	Results and recommendations
and analysis of the pre- and post-training interview schedules	<p>recordings proved to be more time-consuming compared to audio recordings only. Thus, for the main study, only audio recordings of interviews will be done, and interviews will not be transcribed, but rated directly from the audio recordings.</p> <ul style="list-style-type: none"> <li>- The coding process worked well; however, statistical analysis of the data was done qualitatively due to the small sample size.</li> </ul>
<p>The following were assessed with respect to the training programme:</p> <ul style="list-style-type: none"> <li>- integrity of the training in relation to adherence to training content and competent execution</li> <li>- suitability of the training context</li> <li>- clarity of instructions given during training</li> <li>- suitability of training methods and teaching aids</li> <li>- suitability of video material</li> <li>- sequence and pacing of training content, and time taken</li> <li>- participants' interest and benefit derived</li> <li>- influence of training on parents orientations to and definitions of problems</li> </ul>	<p>As above, the overall findings were generally positive</p> <ul style="list-style-type: none"> <li>- Integrity ratings were positive, with ratings of 4 (good) and one rating of 3 (satisfactory), which related to the pacing of content. The ratings were discussed with the rater, and suggested changes were made for the main study.</li> <li>- The training context was generally adequate.</li> <li>- Instructions were adequate. To include instruction for video observation on the power-point slide for the main study.</li> <li>- Training methods, teaching aids, and video material were enjoyed by participants. They requested more power-point slideshows as they found the content very meaningful. Parents also commented positively on the You-tube video and the story of the 'warrior mum'; these made them realize that people faced different problems but their attitude was most important in getting them through. Modifications were thus made for the main study.</li> <li>- Problems were encountered with pacing, as the content was covered in three days over 10 hours. The problem is unlikely to occur in the main study since training is planned for four days over 16 hours.</li> <li>- Participants requested more time to practice the problem definitions skills during training. In addition, they preferred training sessions to be 4 hours to facilitate learning.</li> <li>- Participants' reports on the training and benefit derived were largely positive.</li> <li>- Qualitative analysis of findings indicated that the training had a positive effect on parents' orientations to and definitions of problems, with definitions affected to a greater degree than orientations. Parents' orientations in the pre- and post-training evaluations were positive, with a slightly greater positive shift in the post-training evaluation. The greatest shifts occurred in the dimensions of problem attribution and problem appraisal. Again, due to the small sample size, quantitative methods could not be employed to ascertain statistical significance of changes.</li> </ul>

The recommended changes were made to the detailed training plan (Appendix U). The pre-experimental phase of the study contributed to the development and validation of the two interview schedules and the training programme. The in-depth validation process ensured that the assessment measures and intervention programme were directly applicable to the aim and objectives of this study and therefore ready for use in the experimental phase.

### 3.4.2 Experimental Phase

The experimental phase was presented in six distinct steps, namely, participant selection; pre-training interviews; allocation of participants to experimental and control groups, and establishing functional equivalence of the groups; implementing POD training programme with the experimental group; post-training interviews; and lastly, analysis of data.

### **3.4.2.1 Participant selection**

The following section provides an outline of the participant selection process, the description of the participants and the training context.

#### **3.4.2.1.1 Participant selection process**

The study population was parents of young children with communication disabilities, secondary to an established risk factor. To facilitate the writing process, the term ‘parent’ is used “in a functional and not biological sense”, as done by Dunst’s (2004) in his integrated model of early childhood intervention and family support. Ethical clearance was obtained from the University of Pretoria’s Ethics Committee (Appendix AE). Thereafter, permission was secured from the South African Department of Health (Appendix AF) and the Chief Executive Officers of three public hospitals in the Kwa-Zulu Natal province, to conduct the study at the Speech-Language Therapy Departments at each hospital. Participant selection criteria were detailed as follows:

##### **i) Participant selection criteria**

Five criteria were used to select parents as participants in this study:

- Have a young child diagnosed with a moderate to severe communication disability that was secondary to an established disability. Children with an established risk have "... known (expected) patterns of developmental delay accompanying whatever places them in the established risk grouping" (Rossetti, 1996:3).
- A parent who is primarily responsible for implementing parenting tasks with the child, for example, feeding, toileting and bathing, since problems are generally experienced in these daily contexts. The need for a positive orientation and accurate descriptions of problems is crucial for accessing effective and sustainable ECCI.
- Volunteer and be willing to participate in the entire study (namely, two interviews and the training programme). Participants’ motivation and attendance during the entire course of the study would affect treatment outcomes (McMillan & Schumacher, 2010).
- Be able to understand and speak English, to enable the researcher to gain an in-depth understanding of the parents' orientation to and definition of problems. According to Babbie & Mouton (2001, p. 271), developing an understanding of a group of people who use a different language raises serious challenges to the aim of obtaining an ‘insider’ or ‘emic’ perspective of the research problem. Moreover, the use of interpreters may introduce a

range of variables that may impede the research process, especially in ascertaining the parent's own orientations (DV1) and skills in problem definition (DV2).

- The child must be between the ages of 0-6 years, receiving ECCI services at a public hospital or assessment and therapy centre for between 0-12 months. The study focuses on the problem orientation and definition skills of parents from low income backgrounds. These parents are most likely to access ECCI services from public health facilities, where services for South African children 0-6 years are free of charge (Office of the Deputy President, 1997). Exposure to ECCI was increased from the initial requirement of 0-3 months to 0-12 months, in order to obtain a suitable sample size for statistical analyses (McMillan & Schumacher, 2010; Babbie & Mouton, 2001). Resident SLTs indicated that parents of children who attended ECCI for 0-3 months were recently diagnosed and were generally reluctant to volunteer as research participants since they were still dealing with the diagnosis. While parents' exposure to ECCI did pose a threat to the study's internal validity because parents' orientation to and definition of problems could be influenced by the intervention received from SLTs, the magnitude of the threat was not perceived to be large, since parents were exposed primarily to communication-based intervention, which did not specifically target the five dimensions of problem orientation or the two dimensions of problem definition in the manner intended for this study.

## **ii) Sampling**

Convenience sampling was used to select 34 parents from two public hospitals and an assessment and therapy centre that was attached to a third public hospital. The three hospitals were located in the eThekweni District in the province of Kwa-Zulu Natal, South Africa, and provided ECI services to the majority of the population from low-income backgrounds.

- Speech-language therapists working at the sites were informed about the study and provided with the participant selection criteria. They were also given a hand-out that they used to inform suitable participants about the study so that participants made an informed choice on whether they wanted to participate in the study or not (Appendix AF). The following factors were highlighted in order to motivate parents to attend: (i) researcher would pay for all transport costs; (ii) interviews and training would be done at venues and times that were convenient for the participant; (iii) the benefits of training for parents included learning how to turn problems into challenges that parents could manage while parenting their child with a disability, learning how to work as an equal partner with

professionals; and improving their ability to ask professionals for help in ways that ensured that they received the help they needed for themselves and/or their child.

- Therapists obtained informed consent from all participants who met the criteria and were willing to participate. Therapists were then required to complete the Speech-Language Therapy Summary Profile for each participant (i.e., part 4 of Appendix O). The profile contained information on the child's name, date of birth, age, nature of primary disability (established risk) and summary ratings of the child's general developmental skills and severity of communication disability. The latter information served to assess the reliability of information given by parents during the pre- and post- training interview schedules in terms of background information of the child, and parents' descriptions of problems experienced during parenting.
- The researcher collected the profiles, informed consent forms and contact details of participants from the therapist, once all participants were selected.

### **iii) Allocation of participants to experimental and control groups and establishing functional equivalence of groups**

- As group allocation presented a threat to the internal and external validity of research in this design (McMillan & Schumacher, 2010; Cresswell, 2014), innovative methods were used to minimize such threats. The criterion of parents' availability to attend a four-day versus one-day training programme was selected, thereby minimizing researcher bias and strengthening external validity. The one-day programme was the courtesy training offered to parents in the control group. During pre-training interviews, all parents indicated willingness to participate in training, thus excluding motivation as a potential threat. Parents were informed verbally about the broad aim and benefits of training, the two programmes offered, and the dates, times and venues for each. They were told that the four-day programme provided greater support in enabling parents to adopt positive perceptions and communication skills when seeking help from professionals, but that attendance on all four days was compulsory. In contrast, the one-day programme provided an in-depth overview of the training. Parents were also informed that the researcher would pay for their transport costs to attend either programme. Of the 34 parents, 15 agreed to attend the four-day training and were assigned to the experimental group, and 19 agreed to attend the one-day training and were assigned to the control group. Factors that influenced parents' selection of training programme included work, child-care and family commitments.

- To ensure reliable outcomes, it was important that both groups were functionally equivalent at pre-training in order to attribute post-training differences between the groups with confidence to the training received. Although all the selected participants complied with the same selection criteria, seven possible confounding variables were identified (Terre Blanche, 1999). Six were biographical variables, (i.e. parents' age, education, family income, language status, and the nature and severity of the child's established and communication disabilities), while the seventh variable was parents' pre-training scores on the Problem Orientation and Problem Definition measures. Functional equivalence of the two groups on the six biographical variables was assessed first in Table 15, followed by the parents' pre-training scores on the two measures (see Tables 20 and 21, in Section 4.2.1). The relevant quantitative statistical methods that were used are reported later under data analysis in Section 3.4.2.5. Data in Table 15 reflect that the two groups were functionally equivalent on five of the biographical variables except for family income ( $p = 0.0383$  at the 5% confidence level). Implications for the reliability of data are discussed in Section 4.2.1, in conjunction with the parents' pre-training scores in problem orientation and problem definition.

### 3.4.2.1.2 Description of participants

Table 15 describes the participants in both the experimental and control groups.

Table 15

*Descriptive information of parents in the experimental and control groups*

Demographic variables	Experimental group (n=15)		Control group (n=19)		Fisher's exact test p value
	n	%	n	%	
<b>Participant</b>					
Mother	15	100.00	16	84.21	
Father	-	-	1	5.26	
Caregiver (Grandmother)	-	-	2	10.53	
<b>Age group</b>					
≤20 years	-	-	1	5.26	0.5436
21-30 years	6	40.00	5	26.32	
31-40 years	7	46.67	6	31.58	
41-50 years	1	6.67	4	21.05	
>50 years	1	6.66	3	15.79	
<b>First language and ethnic group</b>					
English/Indian	5	33.33	7	36.84	0.8375
Urdu/Indian	-	-	1	5.26	
isiZulu/Black	9	60.00	11	57.89	
English/Coloured	1	6.67	-	-	
<b>Highest Education</b>					
Did not complete high school	2	13.33	4	21.05	0.1223

	Experimental group (n=15)		Control group (n=19)		Fisher's exact test p value
	n	%	n	%	
<b>Demographic variables</b>					
Completed high school	12	<b>80.00</b>	9	<b>47.37</b>	
Tertiary education	1	6.67	5	26.32	
Postgraduate education	-	-	1	5.26	
<b>Marital status</b>					
Married	7	<b>46.67</b>	10	<b>52.63</b>	
Single	7	<b>46.67</b>	9	47.37	
Living with partner	1	6.66	-	-	
<b>Employment status</b>					
Employed	3	20.00	8	42.11	
Unemployed	12	<b>80.00</b>	11	<b>57.89</b>	
<b>Physical health</b>					
Excellent	9	<b>60.00</b>	7	36.84	
Good	6	40.00	8	<b>42.11</b>	
Not so good	-	-	4	21.05	
<b>Mental health</b>					
Excellent	7	<b>46.67</b>	7	36.84	
Good	5	33.33	9	<b>47.37</b>	
Not so good	3	20.00	3	15.79	
<b>Total family income per month</b>					
R501-R1000	1	6.67	1	5.26	<b>*0.0383</b>
R1001-R1500	8	<b>53.33</b>	3	15.79	
R1501-R2000	-	-	5	26.32	
R2001-R3000	3	20.00	2	10.53	
>R3000	3	20.00	8	<b>42.11</b>	
<b>Child's age</b>					
0-2 years	1	6.66	2	10.53	
2 years 1 month - 4 years	7	<b>46.67</b>	5	26.32	
4 years 1 month - 6 years	7	<b>46.67</b>	12	<b>63.15</b>	
<b>Primary medical diagnosis (Established risk factor)</b>					0.8682
Chromosomal anomalies (Down syndrome)	3	20.00	5	26.32	
Neurological disorders (cerebral palsy, seizures)	7	<b>46.67</b>	9	<b>47.37</b>	
Inborn errors in metabolism	1	6.67	-	-	
Sensory disorders (visual impairment)	-	-	1	5.26	
Atypical developmental disorder (autism spectrum disorder)	3	20.00	4	21.05	
Severe infectious disease (meningitis)	1	6.67	-	-	
<b>Severity of the child's communication disability</b>					0.7241
Moderate to severe	6	40	6	31.58	
Severe	9	<b>60</b>	13	<b>68.42</b>	
<b>SLT's informal analysis of parents' physical health</b>					
Good	15	<b>100.00</b>	18	<b>94.74</b>	
Satisfactory	-	-	1	5.26	
<b>SLT's informal analysis of parents' mental health</b>					
Good	13	<b>86.67</b>	18	<b>94.74</b>	
Satisfactory	2	13.33	-	-	
Poor	-	-	1	5.26	
<b>SLT's informal assessment of parents' coping with parenting a child with a communication disability</b>					
Positive	8	<b>53.33</b>	12	<b>63.16</b>	

Demographic variables	Experimental group (n=15)		Control group (n=19)		Fisher's exact test p value
	n	%	n	%	
Somewhat positive	6	40.00	7	36.84	
Somewhat negative	1	6.67	-	-	

Note: \*significant at 5% level. P values were calculated only for the six variables which were relevant for establishing functional equivalence between the experimental and control groups.

### 3.4.2.1.3 Description of training context

A large room that is usually used for in-service training of staff at one of the hospitals was used to implement the training programme. It was large enough to accommodate the 15 participants, relatively free from distractions and contained the relevant infrastructure for training purposes (as outlined in Section 3.4.1.2).

### 3.4.2.2 Method of data collection, measuring instruments and equipment used in the main study

Data was collected during face-to-face interviews with parents, since interviews did not bias against participants from varied cultural, linguistic and literacy backgrounds (as is prevalent in the South African context) (Babbie & Mouton, 2001). Structured pre- and post-training interview schedules were used to measure parents' orientation to and definition of problems, in order to answer the main research question, namely: 'What is the effect of POD training on parents' orientations to and definitions of problems experienced in parenting young children with moderate to severe communication disabilities?' The research design guided the development of the pre- and post-training schedules and equipment used in the three phases of the main study, namely; pre-training interviews, implementation of the training programme and post-training interviews. The advantages of using structured interview schedules included: (i) rapid appraisal of parents' orientation to and definition of problems; and (ii) ease in incorporating the schedules into professionals' existing methods of assessment, thus strengthening external validity. Table 16 provides an overview of the measuring instruments and equipment used.

Table 16

*Measuring instruments and equipment used in implementing the main study*

<b>Research phases</b>	<b>Measuring instruments</b>	<b>Equipment</b>
Pre-training interviews	<ul style="list-style-type: none"> <li>▪ Biographical Information Questionnaire (Appendix O)</li> <li>▪ Problem Definition Question (Appendix K)</li> </ul>	<ul style="list-style-type: none"> <li>▪ Stopwatch</li> <li>▪ Sanyo voice activated recording system (tape-recorder)</li> <li>▪ TDK 90 minute audio recording cassette (60 minutes of tape)</li> </ul>
Addresses sub -aims: 3.2.3.1 3.2.3.2	<ul style="list-style-type: none"> <li>▪ Problem Orientation Questionnaire (Appendix J)</li> <li>▪ Speech-Language Therapy Summary Profile (part 4 in Appendix O)</li> <li>▪ Interview appointment schedule</li> </ul>	
Implementation of the training programme	<ul style="list-style-type: none"> <li>▪ Training session evaluation form (Appendix V)</li> <li>▪ General evaluation questionnaire (Appendix W)</li> <li>▪ Trainers' reflective diary (Appendix AG)</li> </ul>	<ul style="list-style-type: none"> <li>▪ Sony DCR-HC28E video recorder</li> <li>▪ Video cassettes for recording the training</li> <li>▪ Video material: Video 1 (confident parent sharing positive experiences with ECCD); Videos 2 and 3 (simulation of parents describing problems to SLT in an organized and disorganized manner); Video 4 (are you going to finish strong?).</li> <li>▪ Projector (Optoma EW610ST) and Laptop computer (HP, Compaq 6720s)</li> <li>▪ Large screen</li> <li>▪ PowerPoint slideshows: "We are like pencils" (highlights the importance of one's attitude to life); and "Absolutely fantastic slideshow" (reinforces the need for adopting a positive outlook, despite the circumstances)</li> </ul>
Addresses sub- aim 3.2.3.3		<ul style="list-style-type: none"> <li>Training materials</li> <li>▪ Training Plan (Appendix U)</li> <li>▪ PowerPoint lecture slides</li> <li>▪ Hand-outs ('warrior mum'; getting the help you need when talking to professionals; etc. see Appendix U).</li> <li>▪ Files containing pens and writing paper)</li> <li>▪ Gratitude journals</li> <li>▪ Name tags and attendance register</li> <li>▪ Gift packs</li> </ul>
Post-training interviews	<ul style="list-style-type: none"> <li>▪ Background Information Questionnaire (Appendix O)</li> <li>▪ Problem Definition Question (Appendix K)</li> </ul>	<ul style="list-style-type: none"> <li>▪ Stopwatch</li> <li>▪ Sanyo voice activated recording system (tape recorder)</li> <li>▪ TDK 90 minute audio recording cassette (30 minutes of tape)</li> </ul>
Addresses sub-aims 3.2.3.4 3.2.3.5	<ul style="list-style-type: none"> <li>▪ Problem Orientation Questionnaire (Appendix J)</li> <li>▪ Speech-Language Therapy Summary Profile (part 4 in Appendix O)</li> <li>▪ Interview appointment schedule</li> </ul>	

### **3.4.2.3 Arrangements for participants, training and reliability assessment for the main study**

#### **3.4.2.3.1 Participant arrangements**

- The researcher made telephonic contact with the participants to discuss arrangements for the pre- and post-training interviews (experimental and control groups) and training programme (experimental group only). The researcher thanked the participants for volunteering, and established their preferred choice of venue for the pre- and-post training interviews. The researcher reiterated that all transport costs pertaining to the study would be paid for by the researcher.
- An interview appointment schedule was developed and used to document arrangements for the pre- and post-training interviews as these were discussed on the telephone and according to participants' preferences. The schedule included the following information: participants' names, venue for the interview, contact details (addresses and telephone numbers), interview date and time; and directions to the home, where applicable. The schedule provided a systematic method of documenting arrangements for the interviews. The pre- and post-training interviews were conducted by the researcher.

#### **3.4.2.3.2 Training arrangements**

- The researcher worked closely with the resident SLT in arranging the training programme. These included booking the training venue, ascertaining training equipment that could be used from the venue, organizing catering arrangements, becoming familiar with hospital policies and procedures regarding parent training.
- The researcher visited the venue prior to commencing with the training programme to ensure familiarity with the training set-up, use of equipment and organization of catering set-up.
- Two university students were paid to participate as research assistants during the four training sessions—one to assist the trainer and the other to video record the training on all four days. The duties of the assistants were discussed in a 2-hour briefing session, which included a detailed description of the research and training process, the structure of the training programme and the role of each research assistant. Duties assigned to the first assistant (also referred to earlier as Rater 1 in Section 3.4.1.3.3), included assistance with setting and clearing up the venue before and after training sessions, facilitating

registration when attendance, name tags and writing materials were distributed, organizing catering during tea-breaks, distributing hand-outs and other training materials during training, attending to participant's administrative queries during training, distributing and collecting evaluation forms at the end of each training day, providing transport money and gift packs to parents at the end of each day, rating the integrity of the training after each training day, rating procedural consistency of the pre- and post-training interviews, and checking the accuracy of data capture on Excel spreadsheets before data were submitted to the statistician. The second assistant was a final year information technology student with experience in video recording and managing technical problems, and his duties were to set up the projector, laptop computer and screen for the lectures, video screenings and slideshows, and to obtain a high quality recording of all training events during each session. The need for comprehensive coverage of the programme was stressed to facilitate later evaluations of the integrity of the programme for validity and reliability purposes.

#### **3.4.2.3.3 Reliability assessment arrangements**

- Procedural and measurement reliability were assessed to ensure reliability of the pre- and post-training interviews and the training programme (Schlosser, 2003). Procedural reliability required that the pre- and post-training interview schedules and the training programme were implemented consistently as planned, in order to achieve the intended outcomes (Leedy & Ormrod, 2013; McMillan & Schumacher, 2010). Measurement reliability needed the coding of parents' orientations and definition of problems to be consistent with the definitions of the two dependent variables in the study (Leedy & Ormrod, 2013; McMillan & Schumacher, 2010). The researcher and three external raters ensured that the data collected were reliable for analysis and interpretation.
- Rater 1 was a third year student in Speech-Language Therapy who assisted with the training programme (as already described). Raters 2 and 3 were qualified SLTs working at public hospitals, with five and two years of clinical experience respectively. The procedural consistency of the pre- and post-training interviews and data capture was rated by Rater 1 from the video recordings. Raters 2 and 3 assessed measurement consistency for open-ended questions in the Problem Orientation Questionnaire (i.e. B1 and B4) and Problem Definition Question, from the audio-recordings. The use of external raters was significant to control for researcher bias (Maxwell & Satake, 2006; Schlosser, 2003), particularly since the single open-ended question was the only method used to establish

parents' definitions of problems. The reliability of the training programme was assessed by Rater 1 at two levels, using guidelines from Forgatch et al. (2005), namely the trainer's adherence to the core training content components (i.e., parents' problem orientation and definition behaviours), and the trainer's competent use of clinical and teaching methods to promote changes in parents' problem orientation and definition behaviours. The training was rated using the integrity of the training programme rating sheet (Appendix Y).

- The researcher trained the three external raters for their respective roles. Rater 1, Rater 2 and Rater 3 were trained separately, using guidelines from Forgatch et al. (2005); Schlosser (2003); Sanetti & Kratochwill (2009); and Lewis et al. (1991). All were introduced to the aim and objectives of the study, a brief overview of the constructs of problem orientation and problem definition, a description of the three parts of the interview schedule, the training plan, and the significance of reliability testing to ensure reliable data for analysis and interpretation. Rater 1 was trained to rate procedural consistency of the pre- and post-training interviews, data capture and the integrity of the training programme. The rater was familiarized with items in the rating form for procedural consistency in the interviews and data capturing (Appendix AB) and the detailed training plan which outlined the design and implementation of training (Appendix U), and the integrity of the training programme rating sheet (Appendix Y). The rater's status as a senior student, exposure to clinical and academic university training, and the training received for the study ensured that the rater was competent to provide valid and reliable ratings.
- Raters 2 and 3 were trained to assess measurement consistency for the two open-ended questions in the Problem Orientation Questionnaire (i.e. B1 and B4) and the Problem Definition Question. The raters were trained to reliability in approximately 13 hours (i.e., two three-hour contact sessions, and about seven hours of individual practice specifically for the rating of the Problem Definition Question). The scoring systems for both measures were explained, with more time allocated for the Problem Definition Question. Examples that illustrated the three components of problem definition were used to explain the construct (i.e., what the problem is; desired outcome; obstacles preventing desired outcome). Scripts of good and poor problem definitions were also used (Appendix T). Audio recordings of Pilot study 2 were used to facilitate practice in rating. The raters practiced independently and the researcher evaluated and provided detailed feedback individually and in a group context, using her own ratings as the reliability check.

- Inter-rater percentage agreement between the two raters was thus used and the researcher's ratings provided the reliability check, to ensure measurement consistency. An inter-rater percentage agreement criterion in the range of 80%-90% was set in line with ratings in similar studies (Bernheimer & Weisner, 2007; Lewis et al., 1991).
- Inter-rater percentage agreement was computed using guidelines from Schlosser (2003), namely, number of agreements x 100% divided by number of agreements + number of disagreements. Schlosser (2003) indicated that inter-rating of 20%-40% of data was considered adequate. Following Pilot study 4, both raters achieved 82% inter-rater agreement consistency in coding responses for the Problem Definition Question, and 100% for the Problem Orientation Questionnaire. The consistency ratings were deemed reliable for the main study.
- Use of the researcher's ratings of open-ended questions as a reliability control worked well, and was retained for the main study to manage instances of inter-rater discrepancies. Carter and Iacono (2002) cautioned that high levels of inter-rater agreement following discussions between the raters to resolve discrepancies may reflect the development of new standards between the raters instead of the adequacy of the operational definitions used in the study. Comparisons with the researcher's rating scores therefore provided stricter control, and ensured validity and reliability of the final score.

#### 3.4.2.4 Implementation of the main study

As stated earlier, the main study was executed in three stages, that is, pre-training interviews; implementation of the training programme; and post-training interviews. Table 17 illustrates the implementation process as it unfolded, and a description of each phase follows.

Table 17

##### *Implementation of the research schedule*

<b>Time period (Weeks 1-13)</b>	<b>Research schedule</b>
Week 1 - 2 (14 days)	Pre-training interviews with 34 participants <ul style="list-style-type: none"> <li>- Experimental group (n=15)</li> <li>- Control group (n=19)</li> </ul>
Week 3 - 4 (12 days)	<ul style="list-style-type: none"> <li>- Researcher checked accuracy of data capturing and scored parent responses on DV1 and DV2</li> <li>- Preliminary analysis of parents' background information, and performances on DV1 (orientation to problems) and DV2 (definition of problems)</li> <li>- Findings were used to identify key areas that required greater focus during training.</li> </ul>

<b>Time period (Weeks 1-13)</b>	<b>Research schedule</b>
(1 day)	The findings were similar to those obtained in the pilot study. Participants in the experimental group were contacted and informed about training arrangements. Transport arrangements were finalized.
(2 days)	Training arrangements were finalized. Final check of venue; training plan, equipment, research assistants, catering arrangements; transport of research assistants
Week 5 (4 days)	Day 1: Training programme commenced: experimental group only Day 2: Training programme continued: experimental group only Day 3: Training programme continued: experimental group only Day 4: Training programme concluded: experimental group only
Week 6 - 7 (14 days)	Post-training interviews with 34 participants from the experimental and control group Integrity of the training programme assessed by Rater 3.
Week 8 – 11 (28 days)	Rater 3 and Rater 4 rate pre- and post-training interviews (DV1 and DV2)
Week 12 (3 days)	Data capture onto Excel spreadsheet and data checked by research assistant
Week 13	Data submitted to statistician for analysis

#### **3.4.2.4.1 Pre-training interviews**

- The day before scheduled interviews, participants were contacted by telephone to remind them of the interviews and to check that prior arrangements were still in place.
- Pre-training interviews were conducted at venues that were suitable for parents. Most interviews took place at public hospital Speech-Language Therapy Departments, where parents accessed ECCI. The remaining ones took place at parents' homes and workplaces. To ensure that parents were able to focus on the interview questions and provide relevant responses, the need for child-care support for approximately one hour during the interview was stressed for interviews that occurred at the home, while the need for a quiet environment free from distractions was emphasized for interviews scheduled in work contexts. Interviews at the hospital occurred in a therapy room that was located in a quiet area of the department, to facilitate audio recordings.
- An interview checklist was used to guide the interview and ensure that the relevant processes occurred. Items on the checklist included greeting and introduction; brief explanation of the purpose of the study and processes that would occur in the interview; obtaining informed consent; implementing the Biographical Information Questionnaire, Problem Definition Question and Problem Orientation Questionnaire; training programme arrangements (experimental group), and post-training interview (control group); providing money for transport; and finally to thank parent and conclude interview.
- The anonymity of parents and confidentiality of information provided were emphasized to ensure that parents felt comfortable to share their experiences. Parents were told that their names were known to the researcher only, and all data processing would relate to a participant number. The researcher acknowledged that some of the information requested

dealt with sensitive topics, but urged parents to be honest in their responses. It was pointed out that the researcher would remain open and caring no matter what their response was, since the intention was to learn more about parents' needs and not to judge them. The information would then be used to develop the training programme in ways that addressed their needs. In this way, control of socially desirable responses was addressed.

- Parents were also informed that interviews were audio recorded to ensure that all relevant information were captured; that if they wished they could have access to the audio recordings to ensure that it contained the correct information. Further information that was given to the parent is contained in the informed consent form (Appendix AF).
- All interviews were conducted by the researcher, thus enhancing consistency of the interviewing process. To address issues of subjectivity and bias, guidelines provided by Babbie and Mouton (2001); McMillan and Schumacher (2010) and Hill, Thompson and Williams (1997) were followed. The researcher's profession as a speech-language therapist and 22 years of experience in interviewing parents from backgrounds similar to those of the participants ensured the use of appropriate interviewing skills in obtaining the data. In addition, the researcher's in-depth understanding of the research topic and interview schedule allowed for appropriate responses to parents' questions, while careful attention was paid to adhering to the standard format of the measures—for example, following restrictions placed on probing techniques when eliciting parents' definitions of problems. Nevertheless, the researcher's close proximity to the study in itself may result in bias. To mitigate any potential bias, every effort was made to adopt a neutral stance and follow the structured format of the interview schedule as closely as possible. Overall, the researcher's personal characteristics in terms of age, educational level, professional training, interviewing experience, racial background, and gender fit the variables outlined by McMillan & Schumacher (2010) as those that have a facilitating influence on participants' responses.
- From the outset, the researcher showed genuine interest and was flexible in adapting to the participants interaction style to create an easy and comfortable interview context.
- The sequence followed in administering the data collection instruments were: (1) Biographical Information Questionnaire, (2) Problem Definition Question, and (3) Problem Orientation Questionnaire. Data collection for all three measures were audio recorded.

- The researcher read the instructions and questions and recorded participants' responses on the questionnaires for (1) and (3). Clarification of questions was provided upon parents' requests.
- During the administration of the Problem Orientation Questionnaire (2), parents were presented with a copy of the questionnaire typed in size 14 font for easy visibility. Parents used the copy to illustrate their choice of responses from the provided alternatives.
- In concluding the interview, the researcher thanked the parent and gave R20 to those who had the interview at the hospital to cover their transport expenses. Parents in the experimental group were informed about arrangements for the training programme. Parents in the control group were informed about arrangements for the next interview, and the one-day training programme thereafter.
- To facilitate the training process, the researcher scored parents' responses on the Problem Orientation Questionnaire and the Problem Definition Question in order to identify dimensions of the two dependent variables that required specific attention during training. The researcher's scores, however, were not used during the data analysis phase.

#### **3.4.2.4.2 Implementation of the training programme**

- Participants allocated to the experimental group were contacted telephonically one week before the training programme to remind them of the arrangements. In accordance with participants' preference, a 16-hour training programme was structured into four four-hour sessions from 09h00 to 13h00, and presented over four days in one week.
- The main goal of the programme was to provide parents with knowledge and experiences that promoted positive changes in their orientations to and definitions of problems when seeking help from professionals, specifically SLTs.
- Table 3.8 outlined the principles that guided training, and these related to the training aims, philosophy, structure, training process, training environment and evaluation. Training was presented in four phases, namely, motivation for changes in parents' problem orientations and definitions during ECCI, initiation of changes, maintenance of changes, and finally evaluation of training. Section 3.4.1.2.1 provided an overview of each phase, while Appendix U presents the detailed training plan that was followed for each phase. The training plan included the parent competency and the targeted learning

domain, training aims and motivation, training sessions and the content covered in each, training methods and the equipment used, and finally, the evaluation of training.

- Although the training plan was followed strictly with respect to content and sequence to minimize experimenter bias, flexibility within the plan was vital to follow the learning needs of individual participants (Barnett et al., 2003; Dunst & Trivette, 2009).
- Based on the principle that changes in behaviour are predicated on changes in awareness and attitudes (Peter, 1992), training was designed to challenge parents' current beliefs about their children's disabilities, their role as parents, and the information that they should communicate to professionals when seeking help in ECCI. Relevant teaching methods (e.g. parents sharing their stories, guided reflection) and resources (e.g. real-life and simulated video recordings; inspirational power-point slide shows) were used to stimulate new ways for parents to think about the orientation and problem definition skills that best facilitate their parenting roles as decision-makers and help-seekers for children with moderate to severe communication disabilities. Opportunities were provided to ensure that the recommended orientation and problem definition skills were integrated into existing parenting practices during ECCI, to facilitate and maintain behaviour change (Barnett et al., 2003).
- Training sessions were planned and implemented within an open, interactive, participatory format, and drew on the strengths of the participants and trainer.
- Two research assistants supported the trainer; and their duties are listed in Section 3.4.2.3.2.
- Beverages and snacks were provided during the tea breaks. The breaks also provided an opportunity for parents to socialize with each other.
- At the end of each training day, parents were given the relevant homework assignments. They also evaluated the training received for the day on the training session evaluation form (Appendix V). Parents evaluated the entire training programme at the end of training on Day 4, using the general evaluation questionnaire (Appendix W).
- Previous intervention studies that were reviewed in Table 2 (Section 2.3.1), and Table 3 (Section 2.3.2) were used to develop strategies that ensured full parent attendance on the four training days. At the end of each training day parents were given money for transport (R20 per parent per day), one of the listed items per day that was useful for their child or themselves (i.e., pencil case, juice bottle, reflective journals, and box of crayons), and lucky draw gift hampers. The 'lucky draw' was planned in such a way that every parent received a hamper by the end of the four training days.

- On each training day, participants were reminded not to discuss the training or share the hand-outs and resources received with other parents who attended ECCI at the hospitals that they came from—this would have a negative effect on the findings of the study.
- At the end of each training day, the trainer recorded observations and reflections in the trainer’s reflective diary (Appendix AG). The recordings facilitated the training process by highlighting critical issues that required further attention in the programme.
- Rater 1 assessed the integrity of the training programme at the end of each day, using the integrity of the training programme rating form (Appendix Y). However, training over the four days were video recorded, to corroborate the measurement of treatment integrity, if required.

#### **3.4.2.4.3 Post-training interviews**

- Post-training interviews commenced with the control and experimental groups in the week following the training programme ended. The venues for the interviews were the same as those used during pre-training for each participant.
- The interview format was similar to that followed during the pre-training interviews, and comprised the Background Information Questionnaire, Problem Definition Question and Problem Orientation Questionnaire. For the Background Information Questionnaire, however, parents were asked to report only on information that had changed from that given in the pre-training interview. The main headings of the questionnaire were read out aloud to facilitate the process. No changes were made when the remaining two measures were implemented.
- Interviews were audio recorded and each interview was approximately 15-20 minutes in duration.
- At the conclusion of the interview, participants were thanked for participating in the study. Similar to the pre-training phase, parents were given R20 to cover transport expenses for interviews that occurred at the hospital. Parents in the control group were informed of arrangements for the one-day courtesy training programme.

#### **3.4.2.5 Data analysis and statistical procedures**

Procedures for data analysis were addressed during the two phases of the study, and the nature of analysis and statistical procedures that were used are described below. During

the **pre-experimental phase**, the guidelines for data analysis and interpretation were developed for the Problem Orientation Questionnaire (for DV1) and Problem Definition Question (for DV2). Measures of central tendency and variability that were suitable for ordinal data sets were used (Leedy & Ormrod, 2013), in addition to the literature in Sections 2.3.1 and 2.3.2 respectively. The statistical procedures and interpretation guidelines for each measure are described in detail in Appendix I and Appendix M respectively.

During the **main study**, data analysis and statistical procedures were used at *three broad stages* in order to achieve the main aim of the study (Schlosser, 2003; McMillan & Schumacher, 2010; Leedy & Ormrod, 2013). First, to organize and summarize the ordinal data collected from the three measures; second, to establish the reliability of data for meaningful analysis, and third, to use the data to establish whether the training programme had a positive effect on parents' orientation to and definition of problems experienced in parenting young children with moderate to severe communication disabilities.

The **reliability of the data collected** was ascertained at *five levels* (Schlosser, 2003; McMillan & Schumacher, 2010; Leedy & Ormrod, 2013). The *first level* identified participants' response rate for the pre- and post-training interviews and training programme. The *second level* established procedural consistency in the implementation of the three measures during pre- and post-training interviews, and the implementation of the training programme. The *third level* identified measurement consistency during data capture for closed-ended questions from the Biographical Information Questionnaire and Problem Orientation Questionnaire, and data capture and ratings of open-ended questions from the Problem Orientation Questionnaire (questions B1 and B4) and Problem Definition Question (DV2). At the end of data collection each day, Rater 1 (i.e., the research assistant) checked the accuracy of the pre- and post-training data that were captured in the Biographical Information Questionnaire and Problem Orientation Questionnaire—against the audio recordings of the interviews. Parents' responses to the two open-ended questions in the Problem Orientation Questionnaire were also transcribed in the space provided in the questionnaire. The accuracy of the transcriptions was checked by the researcher using the notes taken during the interviews. The open-ended questions in the Problem Orientation Questionnaire and the Problem Definition Question were rated by the two external raters (i.e., Rater 2 and Rater 3), and the researcher.

The **inter-rating and intra-rating** included the following processes. The consistency of the ratings for both measures was evaluated at two points. First, the reliability of the

ratings between the two raters was assessed using inter-rater percentage agreement to ensure that both raters applied the relevant knowledge and skills consistently for the study's two dependent variables. The researcher's ratings served as the reliability control in view of her in-depth knowledge of the key variables and operational definitions (Carter & Iacono, 2002). As motivated in Section 3.4.2.3.3, inter-rater percentage agreement was employed using Schlosser's (2003) formula. The paired *t*-test assessed if differences in raters' scores were statistically significant. In instances of statistically significant differences between the two raters, ratings that were closest to the researcher's were taken as the final score. Second, the reliability of the ratings from each of the two raters was established to eliminate practice effects as a confounding variable (Lewis et al., 1991; McMillan & Schumacher, 2010). Intra-rater agreement assessed each rater's coding-recoding consistency of audio-recordings that were done at the beginning and end of the rating process, for the pre-training data only. After all audio recordings were rated by both raters, each recoded the open-ended questions in the two measures, for five audio recordings that were randomly selected from the initial 10 recordings that were done (Lewis et al., 1991). For the Problem Definition Question, each raters' consistency in rating the three sub-dimensions of Dimension 1 (i.e., what is the problem, why is it a problem, what obstacles prevent problem resolution), and the three sub-dimensions of Dimension 2 (i.e., specificity, concreteness and comprehensiveness of information) was established for the two periods (i.e., initial and final ratings). In total, eight items were rated (i.e., two from the Problem Orientation Questionnaire and six from the Problem Definition Question). Code-recode percentage agreement was calculated using Schlosser' (2003) formula.

The *fourth level* used Fisher's exact test to determine the functional equivalence of the experimental and control groups to ensure that the groups were comparable prior to training.

The final *fifth level* of reliability testing established the social validity of parents' responses during the pre- and post-training interviews and the training programme (Schlosser, 2003).

Descriptive statistics were used to organize and summarize the data collected, and inferential non-parametric statistical procedures were used to establish whether the POD training programme had a statistically significant effect on the experimental group parents' problem orientations and problem definition skills (Leedy & Ormrod, 2013). The Mann-Whitney-U-Test was used to assess for statistically significant differences between the experimental and control groups, while the Wilcoxin Test was used to assess for statistically

significant differences within the two groups. To determine whether the statistically significant differences were practically meaningful for parents in the study, effect size measures were computed using Cohen's  $d$ , and findings were interpreted using Cohen's categories of small, medium and large effect sizes (Cohen, 1988; McMillan & Schumacher, 2010). Data were computerized for statistical analysis using the SAS Statistical Software package (2004). The following levels of analyses were followed for each dependent variable in order to answer the main research question: (i) statistical analysis of individual items in dimensions; (ii) descriptive analysis of items to derive an overall conclusion for each dimension; (iii) descriptive analysis of findings in each dimension to derive an overall conclusion for each dependent variable. The analyses of individual items to derive conclusions at the construct level is not ideal (Wong & Law, 2008), however, empirical information on the theoretical properties of the five dimensions of the construct is limited (Section 2.3) and constrained analysis beyond the individual item level (for example, at the dimension or overall construct levels).

Table 18 summarizes the data analysis procedures for the main study.

Table 18

*Data analysis procedures for the main study*

<b>Aim</b>	<b>Analysis procedure/Test</b>
<i>Stage one:</i>	
To organize and summarize data in the three measures: - Biographical Information Questionnaire	Frequency counts and percentages for all items
- Problem Orientation Questionnaire (DV1)	Means and SDs of all items
- Problem Definition Question (DV2)	Means and SDs of all items
<i>Stage two:</i>	
To determine the reliability of data collected: - response rate for pre- and post-training interviews and training	Frequency counts and percentages for relevant items
- procedural consistency	Means, SDs, Paired $t$ -test
- measurement consistency (inter-rater and intra-rater reliability)	Fisher's exact test
- functional equivalence of the experimental and control groups	
- parents' evaluation of the interviews and training (social validity)	
<i>Stage three:</i>	
To determine the statistical difference between the experimental and control group for parents' orientation to and definition of problems at pre- and post-training (sub-aims 2 and 3)	Mann-Whitney-U-Test for independent samples
To determine the statistical difference within the experimental and control group for parents' orientation to and definition of problems at pre- and post-training (sub-aims 2 and 3)	Wilcoxin Test for dependent samples

Aim	Analysis procedure/Test
To determine the magnitude of statistical differences found between and within the experimental and control groups at pre- and post-training (sub-aims 2 and 3)	Effect size measure – Cohen’s <i>d</i>
To determine the effect of training on parents’ orientation to and definition of problems (main research aim)	Descriptive analysis of: - statistically significant differences between and within the experimental and control groups for parents’ problem orientations and definitions - practical relevance of effect size for parents

*Note.*SD=Standard deviation

### 3.5 Summary

This chapter presented and motivated for the methodology that was used to investigate the effect of POD training on parents’ orientation to and definition of problems experienced in parenting young children with moderate to severe communication disabilities. The research aim, sub- aims and research design were outlined. The two phases of the research process were described in detail. The pre-experimental phase describes the development and validation of the three measures, the training programme, and the results and recommendations of the pilot studies. The experimental phase discusses participant selection criteria and the participants selected, the equipment used, and the implementation of the pre- and post-training interviews and training programme. Finally, the data analysis and statistical procedures are described.

## CHAPTER 4

### Results

#### 4.1 Introduction

The purpose of this study was to determine the effect of POD training on parents' orientation to and definition of problems experienced in parenting young children with moderate to severe communication disabilities. The main research question guides the analysis and discussion of the results according to the main aim and three sub-aims of the study.

The first sub-aim in Section 3.2.3.1 relates to two aspects of the POD training programme, namely, its development and implementation. The development of the training programme was discussed in Section 3.4.1.2. The results in this section focus on the implementation of the training programme, specifically in generating reliable data.

The chapter commences by establishing the reliability of the collected data to ensure valid and reliable interpretation of findings (Leedy & Ormrod, 2013). Thereafter, the main aim of the study is addressed by establishing the effect of training on parents' orientation to and definition of problems. Sub-aims 3.2.3.2 and 3.2.3.3 were achieved by comparing parents' responses before and after training in the experimental and control groups, at two levels—between and within the groups. Parents' responses before and after training are analysed in the five dimensions of the problem orientation variable, and two dimensions of the problem definition variable. Only key findings are presented to accomplish the study's main aim. Figure 5 provides a schematic representation of the results, in relation to answering the study's main research question.

**Main Research Question:**

**4.1** What is the effect of problem orientation and definition training on parents' orientation to and definition of problems experienced in parenting young children with moderate to severe communication disabilities?



**Outline of analysis to answer the main research question**

**4.2 Reliability of data for meaningful analysis and interpretation**



Overview of results for the five levels of reliability assessment:  
*Sub-aim 3.2.3.1 addressed in 4.2.1 and 4.2.4*

- 4.2.1 Integrity of pre- and post-training interviews and POD training programme (response rate and procedural consistency)
- 4.2.2 Inter-rater and intra-rater reliability of measurement
- 4.2.3 Functional equivalence of the experimental and control groups
- 4.2.4 Parents' evaluation of the interviews and training (social validity)



**4.3 Effect of training on:**  
(i) parents' orientation to problems  
(ii) parents' definition of problems



*Sub-aims 3.2.3.2 and 3.2.3.3*

- 4.3.1 Between-group comparisons of parents' orientation to and definition of problems pre- and post-training
- 4.3.2 Within-group comparisons of parents' orientation to and definition of problems pre- and post-training



**4.4** Overall effect of training on parents' orientation to and definition of problems

**Conclusion: Answer to main research question**

Figure 5: Overview of presentation of the results of the study

**4.2 Reliability of data for analysis and interpretation**

The reliability of the data influences meaningful interpretations of parents' orientation to and definition of problems experienced in parenting young children with moderate to severe communication disorders (Cresswell, 2014). Hence, the critical factors outlined in Figure 4 that allude to the internal validity of the study and provide

the context for data analysis and meaningful interpretation are considered as follows: (i) the integrity of the pre- and post-training interviews and POD training programme with respect to response rate and procedural consistency; (ii) inter-rater and intra-rater reliability of open-ended question scores for parents' problem orientation and definition responses; (iii) the functional equivalence of the experimental and control group; and (iv) parents' evaluation of the interviews and training (social validity). A summary of the key results are presented for all factors except the functional equivalence of the groups, which is discussed in detail to support further analysis. Refer to Appendix AH for detailed analysis and conclusions on the reliability of data.

#### **4.2.1 Integrity of the pre- and post-training interviews and POD training programme**

There was a response rate of 100% for the pre- and post-training interviews with the experimental and control groups (n=34), and 100% attendance for the training programme (experimental group only, n=15). Rater 1 used a four-point Likert scale (1=poor; 2=satisfactory; 3=good; 4=very good) to assess procedural consistency in the implementation of the pre- and post-training interviews, data capture and training programme. Results showed high ratings with both interviews and data capture obtaining a score of 4, while the training programme received a score of 3.98. Response rates and procedural consistency in the implementation of the pre- and post-training interviews and POD training programme (with reference to sub-aim 3.2.3.1) were positive, and provided a solid basis for engagement in meaningful interpretations and conclusions.

#### **4.2.2 Inter-rater and intra-rater reliability of open-ended question scores for Problem Orientation and Problem Definition**

Data from all participants in the experimental and control groups (n=34) for the two open-ended questions in the Problem Orientation Questionnaire (B1 and B4 in Appendix J) and the single open-ended Problem Definition Question (Appendix K), were rated by the two external raters and the researcher, with the researcher's ratings providing reliability control to manage inter-rater differences. The rating process and inter-rater and intra-rater reliability assessment procedures were described in Sections 3.4.2.3.3 and 3.4.2.5. Results of both reliability assessments for the pre-training scores

are summarized in Table 19 with greater detail on mean and standard deviation scores provided in Appendix AH.

Table 19

*Inter-rater-reliability of open-ended question scores in the Problem Orientation Questionnaire and Problem Definition Question*

Questionnaire	Areas assessed for inter-rater and intra-rater reliability	Inter-rater and intra-rater agreement result	Conclusion
Problem Orientation Questionnaire (pre-training only)	<p><i>Inter-rater reliability</i> Two open-ended questions were coded independently by the external raters (Raters 2 and 3)</p> <p>The percentage of agreement between the raters was computed: <i>Question B1</i>: parents' perceptions of the initial cause of the child's communication disability <i>Question B2</i>: parents' perceptions of the maintaining cause of the child's communication disability</p> <p><i>Intra-rater reliability</i>: To control for practice effects in coding, raters recoded the two open-ended questions. Coding-recoding percentage agreement between each rater's first and second ratings was computed, for pre-training data only</p>	<p>100% agreement between the two raters - for the two questions at pre-training</p> <p>100% coding-recoding agreement for each rater</p>	<p>Data obtained for the two questions was reliable. Based on the above positive finding, inter-rater reliability was not computed for post-training data.</p> <p>Individual ratings of both raters were reliable. As above, intra-rater reliability was not computed for post-training data.</p>
Problem Definition Question (pre-training only)	<p><i>Inter-rater reliability</i>: One open-ended question was coded independently by two external raters (Raters 2 and 3)</p> <p>The two dimensions and sub-dimensions of parents' problem definitions were rated using a 4-point Likert scale: (i) Overall organization of information to facilitate the SLT's understanding of the problem (with sub-dimensions: what the problem is, why it is a problem, what obstacles prevent problem resolution), and (ii) Overall relevance of information (with sub-dimensions: specificity,</p>	<p><b>(i) Overall organization of information:</b> - 91% inter-rater agreement reflecting high consistency.</p> <p><b>(ii) Overall relevance of information:</b> <i>Result for sub-dimensions:</i> Specificity, concreteness and comprehensiveness of information - Specificity <i>t</i>-test: 0.99 (p=0.3) - Concreteness <i>t</i>-test: 2.11 (p=0.04*) - Comprehensiveness <i>t</i>-test: 0.08 (p=0.9)</p>	<p>Pre-training data of parents' definition of problems are reliable.</p> <p>Based on the above positive finding, inter-rater reliability was not computed for post-training data.</p>

Questionnaire	Areas assessed for inter-rater and intra-rater reliability	Inter-rater and intra-rater agreement result	Conclusion
	<p>concreteness and comprehensiveness of information)            Each area was rated separately with scores ranging from 1-4, reflecting low to high organization and relevance of information.</p> <p>The paired <i>t</i>-test was used to compute whether there was a statistically significant difference between raters</p> <p>Final scores for overall organization and relevance of information were obtained by averaging scores for the three respective sub-dimensions</p> <p>Overall problem definition score was obtained by averaging scores for the two dimensions of problem definition, that is, (i) organization of information and (ii) relevance of information. The dimensions were weighted equally</p>	<p>No significant differences between raters for ratings of specificity and comprehensiveness of information. Significant differences noted for ratings of concreteness of information</p> <p><i>Result for overall relevance of information:</i>  <i>t</i>-test: 0.70 (p=0.5)            No significant differences between scores of the two raters</p> <p><b>Overall problem definition:</b>  <i>t</i>-test: 1.69 (p=0.1)            No significant differences between the scores of the two raters</p> <p>(Refer to Appendix AH for detailed results)</p>	
	<p><i>Intra-rater reliability:</i>            To control for practice effects in coding, raters recoded six items in five of the initial 10 audio recordings, for pre-training data only.            The six items were :</p> <ul style="list-style-type: none"> <li>- Dimension 1 - three sub-dimensions (what the problem is, why it is a problem, what obstacles prevent problem resolution)</li> <li>- Dimension 2 - three sub-dimensions (specificity, concreteness and comprehensiveness of information)</li> </ul>	<p>100% agreement between each rater's first and second ratings, for items in both dimensions.</p>	<p>Individual ratings of both raters were reliable and were therefore not computed for post-training data.</p>

**Note:** \*statistical significance at the 5% confidence level

### 4.2.3 Functional equivalence of groups

It was important for the groups to be functionally equivalent at the outset on two levels: (i) biographical variables (i.e. parents' age, home language, family income, employment status, highest level of education, nature of child's established disability and severity of communication disability), and (ii) the pre-training scores of the problem orientation and problem definition variables. Findings in Table 15 in Chapter 3, Section 3.4.2.1.2 indicate that the two groups were functionally equivalent on all biographical variables except for the family's income ( $p=0.0383$  at the 5% confidence level). The pre-training results for parents' orientation to and definition of problems are presented in Tables 20 and 21 respectively.

Table 20

*Functional equivalence of the experimental and control groups' pre-training scores on the problem orientation variable*

Problem Orientation	Items of Problem Orientation	Experimental Group (n=15)		Control Group (n=19)		p value (Fisher's exact test)
		Mean	SD	Mean	SD	
<b>Problem perception</b>	Recognition of communication disability	3.40	0.73	3.47	0.90	0.4994
	Need for communication intervention	3.60	0.73	3.94	0.22	0.0759
	Importance placed on communication skills	3.80	0.41	3.78	0.41	0.9408
<b>Problem attribution</b>	Initial cause of communication disability	1.80	0.77	2.10	1.10	0.5388
	Attribution of blame	2.86	1.18	3.05	1.22	0.5653
	Effect of established disability on the child's communication	3.20	1.01	3.63	0.83	0.1264
	Maintaining cause of communication disability	1.73	1.03	2.42	1.30	0.1158
<b>Problem appraisal</b>	Appraisal of communication disability as a threat or challenge	2.86	1.06	2.78	1.03	0.7718
<b>Personal control</b>	Expected outcome regarding communication intervention	3.33	0.61	3.31	0.74	0.9392
	Confidence in using own knowledge and skills to help the child	3.06	0.88	3.10	0.93	0.8395
	Confidence in asking family and friends for help	3.20	0.94	2.89	1.24	0.5782
	Confidence in asking professionals for help	3.60	0.63	3.73	0.56	0.4443

Problem Orientation	Items of Problem Orientation	Experimental Group (n=15)		Control Group (n=19)		p value (Fisher's exact test)
		Mean	SD	Mean	SD	
Commitment in terms of time and effort	Estimate of time it will take for child to learn to talk	3.40	0.63	3.89	0.31	<b>0.0068*</b>
	Parent's willingness to devote time to help child	3.86	0.35	3.89	0.31	0.8037
	Parent's commitment of effort to help child	3.93	0.25	4.00	0.00	0.2604

Note: \*statistical significance at the 5% confidence level Scoring: 1=negative orientation 4=positive orientation

Table 20 indicates that the two groups were functionally equivalent in all items in four dimensions of the problem orientation variable—except for one item in the fifth dimension, that is, parents' estimation of the time it would take for the child to learn to communicate.

Table 21

*Functional equivalence of the experimental and control groups' pre-training scores on the problem definition variable*

Two dimensions of problem definition variable	Sub-dimensions of problem definition variable	Experimental group (n=15)		Control group (n=19)		p-value (Fisher's exact test)
		Mean	SD	Mean	SD	
<b>Dimension 1:</b> <b>Overall organization of information</b>	<i>Sub-dimension 1:</i> What is the problem, to whom and why?	1.87	0.83	2.11	0.81	0.3975
	<i>Sub-dimension 2:</i> What is the desired outcome, for whom and why?					
	<i>Sub-dimension 3:</i> What obstacles make it difficult for the parent and/or child to achieve the desired outcomes?					
<b>Dimension 2:</b> <b>Overall relevance of information</b>	Specificity, concreteness and comprehensiveness of information (average score)	1.51	0.59	1.57	0.59	0.8998
<b>Final problem definition</b>		<b>1.70</b>	<b>0.69</b>	<b>1.85</b>	<b>0.67</b>	<b>0.5494</b>

Note: \*statistical significance at the 5% confidence level—Scoring: 1=poor problem definition 4=good problem definition

Table 21 indicates that the two groups performed similarly in the two dimensions of the problem definition variable, and there were no statistically significant

differences in the final problem definition scores. Thus, findings indicate that the groups are functionally equivalent.

In conclusion, there were two statistically significant differences between the groups, namely, family income (a biographical variable), and parents' estimate of the time it would take the child to learn to communicate (one item in the fifth dimension of the problem orientation variable). More parents in the control group (42.11%) had higher monthly incomes of >R3000 compared to the experimental group. The majority in the experimental group (53.33%) had monthly incomes in the range of R1001.00 – R1500.00. Although parents' employment status was not statistically significant between the groups, since the majority in both groups were unemployed, the higher income of the control group is influenced by the greater number of parents employed (42.11%), compared to 20% in the experimental group. On the basis of 'time available to help the child', the parents' employment status would explain why more parents in the control group estimated that it would take slightly more time for the child to learn to communicate, compared to the experimental group (where 80% of mothers were unemployed and thus more available to assist the child). However, it was encouraging to note that family income had no significant effect on any further items in the five dimensions of problem orientation, or the problem definition variable. On this basis, it was assumed that the effect of the two statistically significant differences on the main research question appeared minimal. It was therefore concluded that the two groups were functionally equivalent.

In summary, Tables 19, 20 and 21 clearly reflect that overall, the data were reliable for analysing and interpreting the effect that training had on parents' orientation to and definition of problems.

#### **4.2.4 Parents' evaluation of the training**

To evaluate the implementation of the training programme in sub-aim 3.2.3.1, parents in the experimental group (n=15) evaluated the training programme at two levels: (i) daily, after each training session on Days 1, 2 and 3, to determine if any changes were required to improve the training; and (ii) at the end of the Day 4 training, to determine parents' overall evaluation of the training and interviews. The training and interviews received positive ratings from parents, indicating satisfaction with the

content of the training programme as well as the method of training. Detailed results are presented in Appendix AH.

### **4.3 Effect of training on parents' orientation to and definition of problems**

The main aim of this study was to determine the effect of POD training on parents' orientation to and definition of problems experienced in parenting young children with moderate to severe communication disabilities. To achieve the main aim and sub-aims, data from the two dependent variables (i.e., parents' orientation to problems and parents' definition of problems) were analysed pre- and post-training in the experimental and control groups. An initial analysis using between-group and within-group comparisons were done to address sub-aims 3.2.3.2 and 3.2.3.3.

Between-group comparisons of parents' orientation to and definition of problems used the Mann-Whitney-U-Test to establish the statistical significance of pre- and post-training differences between the experimental and control groups. Difference scores were calculated for items in each dimension (and sub-dimension, where applicable) of the two dependent variables (i.e. parents' orientation to problems and parents' definition of problems). Difference scores were calculated for items in each group by subtracting the pre-training score from the post-training score, and then determining whether this score for each item was statistically significant by computing the *p*-value using the Mann-Whitney-U-Test. Dimensions and sub-dimensions with statistically significant differences in items between the groups were summarized descriptively, for each dependent variable.

However, between-group analyses using the Mann-Whitney-U-Test only establishes whether there is a difference between the groups or not. If there is a difference, the test does not establish whether the difference may be attributed to the training received in the experimental group, or to other variables such as the parents' exposure to the pre-training interview in the control group. Therefore, within-group comparisons were computed using the Wilcoxin Test to establish the statistical significance of pre- and post-training differences within the experimental and control groups. Again, pre-training scores for items in each dimension (and the sub-dimensions of problem definition) were subtracted from the post-training score for each dependent variable. The statistical significance of differences for items within each group was then compared for each dimension of the dependent variables. The findings were summarised descriptively for each dependent variable. Statistically significant

differences noted in each group could then be attributed with a higher level of confidence to the training received in the case of the experimental group or, in the case of the control group, to other factors that precipitated parents' learning and growth, such as exposure to the pre-training interview.

A final examination of findings within and between each dependent variable used descriptive analysis to reach a final conclusion regarding the overall effect of training on parents' orientation to and definition of problems, thus achieving the main aim of the study. Results for the between-group comparison of parents' orientation to and definition of problems are discussed first and illustrated in Tables 22 and 23 respectively. Results for the within-group comparison are discussed thereafter and are provided in Tables 24 and 25 respectively.

#### **4.3.1 Between-group comparisons of parents' orientation to and definition of problems: pre- and post-training**

The first step in ascertaining the effect that training had on parents' orientation to and definition of problems experienced in parenting young children with communication disabilities, commenced with a comparison of parents' scores *between* the experimental and control groups. Between-group comparisons were done independently for the two dependent variables before final conclusions were reached. For each dependent variable it was important to identify the dimensions and the overall number of dimensions that yielded items with statistically significant differences pre- and post-training between the two groups; and items with no statistically significant differences pre- and post-training. Conclusions for each dimension were based on the number of statistically significant items in each, and the effect size. The latter framework of analysis was used to conclude on the overall differences between the groups, pre- and post-training.

Pre-training results in Tables 20 and 21 already established that the experimental and control groups were functionally equivalent in their orientation to and definition of problems at the outset. Both groups were also equally motivated to participate in the training, irrespective of whether it was the four-day training for the experimental group or the one-day (courtesy) training offered to the control group. The following sections compared parents' responses in each dependent variable at pre- and post-training, between the two groups. Between-group comparison of parents'

orientation to problems is discussed first, followed by parents' definition of problems. A summary of findings for each dependent variable will be presented.

#### **4.3.1.1 Between-group comparison of parents' orientation to problems**

Parents' orientations to problems experienced in parenting young children with moderate to severe communication disabilities were evaluated using the Problem Orientation Questionnaire (Appendix J). The five dimensions of parents' orientations to problems were assessed pre- and post-training, namely: (i) problem perception, (ii) problem attribution, (iii) problem appraisal, (iv) personal control and (v) commitment of time and effort. Table 22 illustrates the results after the Mann-Whitney-U-Test was used to compare pre- and post-training differences in the experimental and control group parents' orientations to problems. Cohen's categories of small, medium and large effect sizes were used to identify practical or meaningful effects of noted differences (Cohen, 1988). Guidelines from Steyn (1999, cited in Strydom & Wessels, 2006) were included as well. However, effect sizes were interpreted with caution, since research has found that studies with small sample sizes tend to have effect sizes that are larger than those with large sample sizes (Slavin & Smith, 2009). Hence, conclusions in descriptive analyses were derived largely from the examination of statistically significant differences (i.e., probability values).

Table 22

*Significance of pre- and post-training differences between the experimental and control groups for parents' orientation to problems*

Problem Orientation	Items in each dimension	Experimental group				Control group				<i>p</i> -value Mann-Whitney-U- test	**Effect size Cohen's <i>d</i>
		Pre-training		Post-training		Pre-training		Post-training			
		$\bar{X}$	SD	$\bar{X}$	SD	$\bar{X}$	SD	$\bar{X}$	SD		
<b>Problem Perception</b>	Recognition of the communication disability	3.40	0.73	3.60	0.50	3.47	0.90	3.68	0.67	0.8137	0.0196 <i>Small</i>
	Recognition of the need for communication intervention	3.60	0.73	4.00	0.00	3.94	0.22	3.94	0.22	<b>0.0185*</b>	0.5428 <i>Medium</i>
	Recognition of the importance of communication skills	3.80	0.41	4.00	0.00	3.78	0.41	3.94	0.22	0.7527	0.1016 <i>Small</i>
<b>Problem attribution</b>	Initial cause of the communication disability	1.80	0.77	3.66	0.89	2.10	1.10	2.21	1.18	<b>0.0000*</b>	1.661 <i>Large</i>
	Attribution of blame	2.86	1.18	3.80	0.41	3.05	1.22	3.15	1.16	<b>0.0282*</b>	0.6469 <i>Medium</i>
	Effect of initial cause on the child's communication	3.20	1.01	4.00	0.00	3.63	0.83	3.57	0.90	<b>0.0010*</b>	0.8406 <i>Large</i>
	Maintaining cause of the communication disability	1.73	1.03	4.00	0.00	2.42	1.30	2.57	1.30	<b>0.0000*</b>	2.0418 <i>Large</i>
<b>Problem appraisal</b>	Appraisal of communication disability as a threat or challenge	2.86	1.06	4.00	0.00	2.78	1.03	2.52	1.26	<b>0.0001*</b>	1.3173 <i>Large</i>
<b>Personal control</b>	Expected outcome from communication intervention	3.33	0.61	3.80	0.41	3.31	0.74	3.15	0.89	<b>0.0370*</b>	0.6953 <i>Medium</i>
	Confidence in using own knowledge and skills to help the child	3.06	0.88	3.60	0.50	3.10	0.93	2.78	0.97	<b>0.0085*</b>	0.9592 <i>Large</i>
	Confidence in asking family and friends for help	3.20	0.94	3.86	0.35	2.89	1.24	3.00	1.20	<b>0.0161*</b>	0.6239 <i>medium</i>
	Confidence in asking professionals for help	3.60	0.63	3.86	0.35	3.73	0.56	3.68	0.67	0.1111	0.5139 <i>Medium</i>

Problem Orientation	Items in each dimension	Experimental group				Control group				p-value Mann-Whitney-U- test	**Effect size Cohen's d
		Pre-training		Post-training		Pre-training		Post-training			
		$\bar{X}$	SD	$\bar{X}$	SD	$\bar{X}$	SD	$\bar{X}$	SD		
<b>Commitment of time and effort</b>	Estimate of time it will take for the child to learn to talk	3.40	0.63	3.66	0.61	3.89	0.31	3.84	0.37	<b>0.0141*</b>	0.6976 <i>Medium</i>
	Parents willingness to devote time to help the child	3.86	0.35	3.93	0.25	3.89	0.31	3.89	0.31	0.2604	0.2583 <i>Small</i>
	Parents commitment of effort to help the child	3.93	0.25	4.00	0.00	4.00	0.00	4.00	0.00	0.2604	0.2583 <i>Small</i>

Note: \* statistical significance at the 5% confidence level      Scoring: 1 = negative orientation    4 = positive orientation

\*\*Effect size - indication of practical or meaningful difference

Cohen's category (Cohen, 1988; Steyn, 1999 cited in Strydom & Wessels, 2006)

0.0 - 0.2 = small effect size. In new research, recommend repeating study to ensure that there is an effect.

0.2 - 0.8 = medium/moderate effect size. Recommend a better planned study to provide a more significant result.

> 0.8 = large effect size. Results are significant and of practical value.

**(i) Items in problem orientation that were statistically significant between groups**

Table 22 identifies *statistically significant differences* at the 5% confidence level between the experimental and control groups for items in *four of the five dimensions* of problem orientation. However, the dimensions vary at two levels, that is, the number of statistically significant items in each dimension, and the effect sizes. Considering the two levels, the four dimensions are sequenced in order of those with the most statistically significant items to those with the least.

All the items of Problem attribution and Problem appraisal were significant. Problem attribution evaluated parents' perceptions of the causes of the child's communication disability. Statistically significant differences in all four items were present ( $p=0.0000$ ;  $p=0.0282$ ;  $p=0.0010$ ;  $p=0.0000$ ), with large effect sizes in three, and a medium effect in one item. The three items with large effect sizes were parents' perceptions of: (i) the initial cause of the child's communication problem, (ii) the effect that the established disability would have on the child's communication, and (iii) the maintaining cause of the problem. A medium effect size was evident in parents' attribution of blame for the child's communication disability. Problem appraisal had only one item, namely, parents' perceptions of the child's communication as a threat or challenge. The finding was statistically significant ( $p=0.0001$ ) with a large effect size. The dimension of personal control showed statistically significant differences in three of four items ( $p=0.0370^*$ ;  $p=0.0085^*$ ;  $p=0.0161^*$ ;  $p=0.111$ ). Probability values ( $p$ -values) are listed in the sequence that items appear in Table 4.4. Effect sizes ranged from medium (i.e., parents' expectations regarding communication outcomes, and their confidence in asking family and friends for help), to large (i.e., parents' confidence in using their own knowledge and skills to help the child). In the dimension of problem perception only one of the three items had a statistically significant difference ( $p=0.8137$ ;  $p=0.0185^*$ ;  $p=0.7527$ ), with a medium effect size (i.e., parents' recognition of the need for communication intervention).

**(ii) Problem orientations that were not statistically significant between groups**

Parents' commitment of time and effort to help the child achieve his/her full developmental potential was the only dimension where all three items were not statistically significant ( $p=0.0141$ ;  $p=0.2604$ ;  $p=0.2604$ ). The findings indicate that both groups performed similarly before and after training. In both groups, parents were committed to devote all the time they had and to put in a lot of effort to help their child.

In summary, between-group analyses clearly highlighted statistically significant pre- and post-training differences with large effect sizes in items in two dimensions of parents' problem orientation, namely, problem attribution and problem appraisal. To a lesser extent, statistically significant differences with predominantly medium effect sizes were also noted in items in the dimension of personal control, with the least difference noted in items in the dimension of problem perception. There were no statistically significant differences in any items in the dimension of parents' commitment of time and effort, indicating that parents performed consistently at pre- and post-training.

#### **4.3.1.2 Between-group comparison of parents' definition of problems**

Parents' definitions of problems experienced in parenting young children with moderate to severe communication disabilities were evaluated using one open-ended question in the Problem Definition Question (Appendix K). The question asked parents to describe the problem and the help that they wanted from the SLT. Two dimensions of parents' skill in defining problems were evaluated pre- and post-training. Firstly, their ability to present the problem in an organized format that considered three aspects: (a) what is the problem, to whom and why; (b) what is the desired outcome, for whom and why; and (c) what obstacles hindered the attainment of desired outcomes for the child and parent. Secondly, their ability to provide relevant information about the child's communication problem and other associated challenges, if present. Relevant information is defined as specific, concrete and comprehensive (D'Zurilla & Nezu, 1999; 2010) and was scored accordingly

Parents' responses were rated by two external raters. Refer to Table 19, where these are identified. A 4-point Likert scale was used with a score of 1 reflecting extremely poor problem definition skills and a score of 4 reflecting excellent problem definition skills (Appendix K). Inter-rater reliability and intra-rater agreement reliability were generally good, indicating reliable data (refer to Section 4.2.2). Table 23 provides the results after the Mann-Whitney-U-Test was used to compare differences between the experimental and control group parents' definitions of problems. Cohen's categories of small, medium and large effect sizes were used to identify meaningful effects of noted differences (Cohen, 1988). Guidelines from Steyn (1999, cited in Strydom & Wessels, 2006) were included as well.

Table 23

Significance of pre- and post-training differences between the experimental and control groups for parents' definition of problems

Problem Definition	Sub-dimensions of Problem Definition Variable	Experimental group (n=15)				Control group (n=19)				p-value Mann-Whitney-U-Test	**Effect size Cohen's d
		Pre-training		Post-training		Pre-training		Post-training			
		$\bar{X}$	SD	$\bar{X}$	SD	$\bar{X}$	SD	$\bar{X}$	SD		
<b>Dimension 1: Overall organization of information</b>	<b>Overall organization of information</b> <i>Sub-dimension 1:</i> What is the problem, to whom and why? <i>Sub-dimension 2:</i> What is the desired outcome, for whom and why? <i>Sub-dimension 3:</i> What obstacles make it difficult for the parent and/or child to achieve the desired outcomes?	1.87	0.83	3.33	0.49	2.11	0.81	2.32	0.67	<b>0.0003*</b>	<b>1.3721</b> <i>large</i>
<b>Dimension 2: Overall relevance of information (specificity, concreteness and comprehensiveness of information)</b>	<i>Sub-dimension 1:</i> Specificity of information	1.60	0.65	3.18	0.51	1.68	0.66	1.67	0.56	<b>0.0000*</b>	<b>2.5471</b> <i>large</i>
	<i>Sub-dimension 2:</i> Concreteness of information	1.49	0.57	3.16	0.65	1.63	0.64	1.49	0.52	<b>0.0000*</b>	<b>3.0051</b> <i>large</i>
	<i>Sub-dimension 3:</i> Comprehensiveness of information	1.48	0.55	3.07	0.69	1.48	0.49	1.51	0.49	<b>0.0000*</b>	<b>2.5652</b> <i>large</i>
	<b>Overall relevance of information (average score)</b>	1.51	0.59	3.15	0.63	1.57	0.59	1.55	0.50	<b>0.0000*</b>	<b>2.9311</b> <i>large</i>
<b>Final problem definition (average of Dimensions 1 and 2)</b>		<b>1.70</b>	<b>0.69</b>	<b>3.27</b>	<b>0.46</b>	<b>1.85</b>	<b>0.67</b>	<b>1.95</b>	<b>0.52</b>	<b>0.0000*</b>	<b>2.4573</b> <i>large</i>

Note: \*statistical significance at 5% confidence level

Scoring: 1=poor problem definition skills 4=good problem definition skills

\*\*Effect size - indication of practical or meaningful difference. Cohen's category (Cohen, 1988; Steyn, 1999 cited in Strydom & Wessels, 2006):

0.0 - 0.2 = small effect size. In new research, recommend repeating study to ensure that there is an effect; 0.2 - 0.8 = medium/moderate effect size. Recommend a better planned study to provide a more significant result; > 0.8 = large effect size. Results are significant and of practical value.

Table 23 indicates that pre- and post-training differences between the experimental and control groups were statistically significant at the 5% confidence level for the two dimensions of problem definition (i.e., parents' organization of information [ $p=0.0003$ ] and the provision of relevant information [ $p=0.0000$ ]), as well as parents' overall problem definition skills ( $p=0.0000$ ). The effect size for all three dimensions was large. Similar findings were evident for the sub-dimensions of specificity, concreteness and comprehensiveness of information ( $p=0.0000$  respectively).

#### **4.3.1.3 Summary and Conclusion regarding between-group comparisons**

Statistically significant findings were found to varying degrees in four dimensions of problem orientation, with the largest effect sizes seen in parents' problem attributions and problem appraisals, followed by personal control (three out of four items), and lastly problem perception (one out of three items). There were no statistically significant differences between the groups regarding commitment of time and effort. On the contrary, findings were statistically significant with large effect sizes in the two dimensions of parents' problem definition, that is, presenting information in an organized format and providing relevant information, as well as their overall problem definitions. Therefore, in the initial step to addressing sub-aims 3.2.3.2 and 3.2.3.3 it is concluded that there were statistically significant differences between the experimental and control groups, with greater differences noted in parents' definition of problems compared to their orientation to problems. However, to establish whether the differences between the groups can be attributed confidently to the training provided to the experimental group, further analysis of within-group comparisons is necessary.

#### **4.3.2 Within-group comparison of parents' orientation to and definition of problems: pre- and post-training**

To complete sub-aims 3.2.3.2 and 3.2.3.3, this section investigates whether pre- and post-training differences in items *within* the experimental and control groups are statistically significant. Differences within the groups would clearly establish whether the training condition was the only factor that could be attributed to any changes noted in parents' orientation to and definition of problems. Parents' pre-training scores were subtracted from the post-training scores, for all items within each group. The Wilcoxin Test was used to ascertain whether the difference was statistically significant for items in each dimension of parents' orientation to and definition of problems. A format similar to that of the previous section was followed by

analysing parents' orientation to problems first, and then parents' definition of problems. Results are illustrated in Tables 24 and 25 respectively.

#### **4.3.2.1 Within-group comparison of parents' orientation to problems**

Table 24 demonstrates statistically significant findings at the 5% confidence level to varying degrees in three of the five dimensions of problem orientation within the experimental group. Statistically significant findings were identified in all items in the dimension of problem attribution ( $p=0.0005$ ;  $p=0.0313$ ;  $p=0.0156$ ;  $p=0.0002$ ) and the single item in problem appraisal ( $p=0.0010$ ). Large effect sizes were now only evident in two items of problem attribution, i.e., parents' perception of the initial and maintaining causes of the communication disability and in the single item regarding parents' appraisal of the communication as a threat or challenge. The dimension of personal control showed only one out of three items that was statistically significant, namely, parents' confidence in asking family and friends for help ( $p=0.0156$ ). The item had a medium effect size. There were no statistically significant findings in the two dimensions of problem perception and parents' commitment of time and effort.

Within-group differences in the control group were not statistically significant in the five dimensions. The findings indicate that the control group parents' orientations to problems remained fairly consistent before and after training.

Table 24

Significance of pre- and post-training differences within the experimental and control groups for parents' orientation to problems

Problem Orientation	Items in each dimension	Experimental group (n=15)						Control group (n=19)					
		Pre-training		Post-training		p value Wilcoxin Test	Effect size** Cohen' s d	Pre-training		Post-training		p- value Wilcoxin Test	**Effec t size Cohen' s d
		$\bar{X}$	SD	$\bar{X}$	SD			$\bar{X}$	SD	$\bar{X}$	SD		
<b>Problem perception</b>	Recognition of the communication disability	3.40	0.73	3.60	0.50	0.2500	0.2714 <i>small</i>	3.47	0.90	3.47	0.90	0.2500	0.0001 <i>small</i>
	Recognition of the need for communication intervention	3.60	0.73	4.00	0.00	0.1250	0.5428 <i>medium</i>	3.94	0.22	3.94	0.22	1.0000	0.0004 <i>small</i>
	Recognition of the importance of communication skills	3.80	0.41	4.00	0.00	0.2500	0.4831 <i>medium</i>	3.79	0.42	3.79	0.42	0.2500	0.0002 <i>small</i>
<b>Problem attribution</b>	Initial cause of the communication disability	1.80	0.77	3.66	0.89	<b>0.0005*</b>	<b>2.0746</b> <i>large</i>	2.11	1.10	2.11	1.10	1.0000	0.0000 <i>small</i>
	Attribution of blame	2.86	1.18	3.80	0.41	<b>0.0313*</b>	<b>0.7861</b> <i>medium</i>	3.05	1.22	3.05	1.22	0.5000	0.0000 <i>small</i>
	Effect of initial cause on the child's communication	3.20	1.01	4.00	0.00	<b>0.0156*</b>	<b>0.7888</b> <i>medium</i>	3.63	0.83	3.63	0.83	1.0000	0.0001 <i>small</i>
	Maintaining cause of the communication disability	1.73	1.03	4.00	0.00	<b>0.0002*</b>	<b>2.1947</b> <i>large</i>	2.42	1.30	2.42	1.30	0.6875	0.0000 <i>small</i>
<b>Problem appraisal</b>	Appraisal of communication disability as a threat or challenge	2.86	1.06	4.00	0.00	<b>0.0010*</b>	<b>1.0691</b> <i>large</i>	2.78	1.03	2.52	1.26	0.2500	0.0001 <i>small</i>

Problem Orientation	Items in each dimension	Experimental group (n=15)						Control group (n=19)					
		Pre-training		Post-training		p value <i>Wilcoxin Test</i>	Effect size** <i>Cohen's d</i>	Pre-training		Post-training		p- value <i>Wilcoxin Test</i>	**Effect size <i>Cohen's d</i>
		$\bar{X}$	<i>SD</i>	$\bar{X}$	<i>SD</i>			$\bar{X}$	<i>SD</i>	$\bar{X}$	<i>SD</i>		
<b>Personal control</b>	Expected outcome of communication intervention	3.33	0.61	3.80	0.41	0.0625	0.7561 <i>medium</i>	3.31	0.74	3.15	0.89	0.7656	0.0001 <i>small</i>
	Confidence in using own knowledge and skills to help the child	3.06	0.88	3.60	0.50	0.0547	0.6035 <i>medium</i>	3.10	0.93	2.78	0.97	0.2344	0.0001 <i>small</i>
	Confidence in asking family and friends for help	3.20	0.94	3.86	0.35	<b>0.0156*</b>	<b>0.7083 <i>medium</i></b>	2.89	1.24	3.00	1.20	0.5000	0.0000 <i>small</i>
	Confidence in asking professionals for help	3.60	0.63	3.86	0.35	0.1250	0.4215 <i>medium</i>	3.73	0.56	3.73	0.56	1.0000	0.0000 <i>small</i>
<b>Commitment of time and effort</b>	Estimate of time it will take for the child to learn to talk	3.40	0.63	3.66	0.61	0.1250	0.4215 <i>medium</i>	3.89	0.31	3.89	0.31	1.0000	0.0000 <i>small</i>
	Parents' willingness to devote time to help the child	3.86	0.35	3.93	0.25	1.0000	0.1893 <i>small</i>	3.89	0.31	3.89	0.31	1.0000	0.0000 <i>small</i>
	Parents commitment of effort to help the child	3.93	0.25	4.00	0.00	1.0000	0.2583 <i>small</i>	4.00	0.00	4.00	0.00	1.0000	0.0000 <i>small</i>

Note: \* statistical significance at the 5% confidence level Scoring: 1=negative orientation 4=positive orientation

\*\***Effect size** - indication of practical or meaningful difference. Cohen's category (Cohen, 1988; Steyn, 1999 cited in Strydom & Wessels, 2006):

0.0 - 0.2 = small effect size. In new research, recommend repeating study to ensure that there is an effect; 0.2 - 0.8 = medium/moderate effect size. Recommend a better planned study to provide a more significant result; > 0.8 = large effect size. Results are significant and of practical value.



In addressing sub-aim 3.2.3.2, overall findings indicate statistically significant differences to varying degrees in items in three dimensions of parents' orientations in the experimental group. The differences were largely evident in items in the dimensions of problem attribution and problem appraisal, and minimally evident in items in the dimension of personal control. No statistically significant effects were seen in items in the dimensions of problem perception and parents' commitment of time and effort to help their child. Statistically significant differences were not present in the control group.

#### **4.3.2.2 Within-group comparison of parents' definition of problems**

In addressing sub-aim 3.2.3.3, Table 25 indicates that pre- and post-training differences within the experimental group were statistically significant at the 5% confidence level for the two dimensions of problem definition, i.e., parents' organization of information ( $p=0.0005$ ) and the provision of relevant information ( $p=0.0001$ ), as well as parents' overall problem definition skills ( $p=0.0001$ ). The effect size for all three was large. All the sub-dimensions of relevant information, i.e., specificity, concreteness and comprehensiveness of information indicate significant differences ( $p=0.0001$ ), again with large effect sizes. Within-group differences in the control group were not statistically significant, indicating that parents in the control group performed consistently in the pre- and post-training interviews as they did not receive any training.

#### **4.3.2.3 Summary and Conclusion regarding within-group comparisons**

For parents' orientation to problems, statistically significant differences were clearly evident in items in the dimensions of problem attribution (all items) and problem appraisal (single item). However, in the dimension of personal control only one out of four items was statistically significant. No statistically significant effects were seen in items in the dimensions of problem perception and parents' commitment of time and effort to help their child. Results for parents' problem definitions showed statistically significant differences in parents' organization of information, the provision of relevant information, and overall problem definitions skills. It is thus concluded that statistically significant within-group findings were evident in the experimental group but not in the control group. Statistically significant differences with large effect sizes were found largely in parents' definition of problems compared to their orientations to problems.

Table 25

*Significance of pre- and post-training differences within the experimental and control groups on parents' definition of problems*

Problem definition	Items in each dimension	Experimental group (n=15)						Control group (n=19)					
		Pre-training $\bar{X}$	SD	Post-training $\bar{X}$	SD	p-value Wilcoxin Test	**Effect size Cohen's d	Pre-training $\bar{X}$	SD	Post-training $\bar{X}$	SD	p-value Wilcoxin Test	**Effect size Cohen's d
<b>Dimension 1: Overall organization of information</b>	<b>Overall organization of information</b> <i>Sub-dimension 1:</i> What is the problem, to whom and why? <i>Sub-dimension 2:</i> What is the desired outcome, for whom and why? <i>Sub-dimension 3:</i> What obstacles make it difficult for the parent and/or child to achieve the desired outcomes?	1.87	0.83	3.33	0.49	0.0005*	1.7589 <i>large</i>	2.11	0.81	2.11	0.81	0.2891	0.0001 <i>small</i>
<b>Dimension 2: Overall relevance of information (specificity, concreteness and comprehensiveness of information)</b>	<i>Sub-dimension 1:</i> Specificity of information	1.60	0.65	3.18	0.51	0.0001*	2.4255 <i>large</i>	1.68	0.66	1.68	0.65	0.9174	0.0000 <i>small</i>
	<i>Sub-dimension 2:</i> Concreteness of information	1.49	0.57	3.16	0.65	0.0001*	2.5739 <i>large</i>	1.63	0.64	1.63	0.64	0.4362	0.0001 <i>small</i>
	<i>Sub-dimension 3:</i> Comprehensiveness of information	1.48	0.55	3.07	0.69	0.0001*	2.2948 <i>large</i>	1.48	0.49	1.48	0.49	0.9720	0.0000 <i>small</i>
	<b>Overall relevance of information (average score)</b>	1.51	0.59	3.15	0.63	0.0001*	2.6219 <i>large</i>	1.57	0.59	1.57	0.59	0.6162	0.0000 <i>small</i>
<b>Final problem definition</b>	<b>Overall organization and relevance of information (average score)</b>	1.70	0.69	3.27	0.46	0.0001*	2.2507 <i>large</i>	1.85	0.67	1.85	0.67	0.3941	0.0000 <i>small</i>

Note: \*statistical significance at 5% confidence level

Scoring: 1=poor problem definition skills

4=good problem definition skills

\*\*Effect size - indication of practical or meaningful difference. Cohen's category (Cohen, 1988; Steyn, 1999 cited in Strydom & Wessels, 2006):

0.0 - 0.2 = small effect size. In new research, recommend repeating study to ensure that there is an effect; 0.2 - 0.8 = medium/moderate effect size. Recommend a better planned study to provide a more significant result; > 0.8 = large effect size. Results are significant and of practical value.

#### **4.4 Overall effect of training on parents' orientation to and definition of problems**

To address the main aim of the study, the following section integrated findings for sub-aims 3.2.3.2 and 3.2.3.3 from the between-group and within-group analyses to derive overall conclusions about the effect of training on parents' orientation to and definition of problems. The section commenced with a comparison of between-group and within-group findings in order to ascertain changes in parents' orientation to and definition of problems that could be attributed confidently to the training provided to the experimental group. The findings were analysed further to clearly establish the nature of statistically significant and non-significant effects of training on parents' orientation to and definition of problems.

##### **4.4.1 Differences *between* and *within* groups: establishing the effect of training**

This section investigated whether pre- and post-training differences between groups were similar to pre- and post-training differences within groups for parents' orientation to and definition of problems. Similar differences would confirm with greater confidence that the training programme was indeed responsible for the differences in the experimental group, as opposed to other confounding variables such as exposure to questions in the pre-training interview. Parents' orientation to problems is discussed first, followed by parents' definitions of problems.

***Parents' orientation to problems:*** The dimensions of problem attribution (four items) and problem appraisal (single item) were the only two that maintained statistically significant findings in both analyses. The dimension of personal control followed with a statistically significant finding in only one out of four items (i.e., confidence in asking family and friends for help). Statistically significant within-group findings in the **six items** can therefore be confidently attributed to the training provided to the experimental group.

Based on the above it was clear that statistically significant differences that were found in three other items in the between-group analyses, were due to factors other than the training. Table 22 identifies these items as one item in the dimension of problem perception i.e., parents' recognition of the need for communication intervention; and two items in the dimension of personal control, that is, parents' expected outcome regarding the child's communication, and their confidence in using their own knowledge and skills to help their child.

***Parents' definition of problems:*** Statistically significant findings remained consistent in the between-group and within-group analyses for parents' organization of information, the provision of relevant information, and overall problem definitions skills. The findings indicate that the significant results in the two dimensions of problem definition and in parents' overall problem definition skills can be attributed confidently to the training provided to the experimental group.

In addressing the main aim of the study, it is therefore concluded that the training programme had a statistically significant effect on parents' orientation to problems and their definition of problems. However, regarding parents' orientation to problems, the effect was limited to orientations concerning causal attributions and appraisals of the child's communication disability, and confidence in asking family and friends for help (in terms of personal control). Hence, it is apparent that the training had a greater effect on parents' definition of problems compared to their orientations to problems.

#### **4.5 Summary**

This chapter presented the results of the study as it related to the main aim and sub-aims. The reliability of the data and participants' evaluation of the training were considered. Analyses of statistically significant differences between groups and within groups were then computed to determine the effect of training on parents' orientation to and definition of problems. Overall findings reflect that the training programme had statistically significant differences in both variables, but that these differences were greater in parents' definition of problems compared to their orientation to problems.

## CHAPTER 5

### DISCUSSION OF RESULTS

#### 5.1 Introduction

The results are discussed in relation to the overall aim of the study, namely, to determine the effect of training in POD on parents' orientation to and definition of problems experienced in parenting young children (0-6 years) with moderate to severe communication disabilities. Key findings are interpreted broadly in relation to parents' competence in seeking help from ECCI, at pre- and post-training levels. Research and clinical implications of the findings are considered.

#### 5.2 Results of parent training in problem orientation and definition: research and clinical implications for supporting parents' help-seeking during ECCI

The main findings indicated overall positive effects of training on parents' problem orientation and definition (Appendix AK). Statistically significant differences were found in items in three of the five dimensions of problem orientation (Table 24). Training supported parents as follows: to appraise their situation as a challenge that they could benefit from, rather than a threat that was harmful to them (problem appraisal); to adopt more positive orientations about the causes of the child's established disability (problem attribution); and to increase their confidence to approach family and friends for help (personal control–self-efficacy). In contrast, statistically significant differences were found in *all* items within the two dimensions of problem definition (Table 25). Training helped parents to select relevant information about their problems and needs, and to communicate it in an organised manner so that SLTs could understand and provide ECCI that met parents' needs. The findings for problem orientation and definition suggested that the positive effects of training were greater for parents' problem definitions, compared to their problem orientations.

The variability of the training effects on parents' problem orientation and definition constituted the main focus of the review and discussion. The key issues included: (i) an analysis of why training in problem orientation had a statistically significant effect on items in only three of the five dimensions; and (ii) an analysis of why training had statistically significant effects on

all items in both dimensions of problem definition. Clinical and research implications are discussed to assist in supporting parents' help-seeking in ECCI.

### **5.2.1 Analysis of key training outcomes in parents' problem orientation: implications for parents' help-seeking in ECCI**

Parents' problem orientation was measured with the use of 15 items that assessed the five dimensions of the problem orientation construct. Table 24 reflects that statistically significant training effects were found in six items from the dimensions of problem attribution, personal control (self-efficacy component), and problem appraisal; but not in nine items from the dimensions of problem perception, personal control (outcome expectancy and self-efficacy), and commitment of time and effort. The difference in findings was interpreted as follows. Firstly, the statistically significant findings identified specific areas where training was effective. Therefore, the findings suggested that these were vulnerable areas which may be compromising the effectiveness of parents' help-seeking in ECCI. Secondly, the non-significant findings identified areas where training was not effective. Parents' problem orientations in these areas were in the positive range, and therefore implied that parents were motivated to initiate and sustain help-seeking in ECCI. Factors that could explain the difference in findings are discussed to ensure that the training outcomes were credible. Relevant research and clinical implications are identified.

#### ***5.2.1.1 Review and implications of statistically significant findings in problem orientation***

A review of the six statistically significant findings was based on Tables 22, 24 and AK1. It was found that positive training effects were the greatest in the dimension of problem attribution, followed by problem appraisal, and lastly, personal control (self-efficacy component). All of the items in the dimensions of problem attribution and problem appraisal maintained statistical significance in the between-group and within-group analyses; and although effect size was interpreted with caution as a result of the small sample size (McMillan & Schumacher, 2010; Satake, 2015), both dimensions contained the three items that had large effect sizes. The positive effect of the training was the greatest in the dimension of problem attribution because the training had the most positive effect on parents' attribution of the maintaining cause of the child's communication disability (pre-and-post-training mean values were 1.73 and 4.00, respectively), followed by attributions of the initial cause (pre- and post-

training mean values were 1.80 and 3.66, respectively). Both were the only items that suggested negative orientations at pre-training in the experimental and control groups. The findings implied that parents' problem attributions maybe the most critical mediators of their motivation to seek help from ECCI. Pre- and post-training findings of parents' problem attributions were therefore reviewed to highlight both the key issues which underpinned their attribution styles, and the clinical implications of these issues for parents' initiation and maintenance of help-seeking in ECCI.

**Review of key findings at pre-training:** Parents' problem attributions reflected their beliefs about the causes, effects and management of disability; and these beliefs were greatly influenced by parents' cultural and religious views (Petersen & Steen, 2002; Harry, 2002; Neely-Barnes & Dia, 2008; Wegner & Rhoda, 2015). Their acceptance of the initial and maintaining causes of disability was critical in mobilising them to seek help (Hamburg & Adams, 1967; Turnbull et al., 1993; Wegner & Rhoda, 2015). Pre-training results revealed that the parents' in both groups attributed the *initial cause* of the child's communication disability correctly in terms of the established disability (e.g. cerebral palsy, autism). All of the parents elaborated on their response by attributing the established disability to internal and/or external factors that hindered positive coping, or alternatively, they indicated that they were unsure of the cause of the established disability. Their overall responses showed that they had difficulty in accepting the initial cause of the established disability. For example, their attribution to internal factors related largely to their cultural beliefs (e.g. *"My father cursed me because I fell pregnant ... I was still studying... I brought shame to the family,"* or *"My husband's family blame me for not doing a prayer before the birth,"*), and self blame (e.g. *"I was too old to have a baby... should have known better..."*); whilst attributions to external factors pertained largely to the negligence of the medical staff during the pregnancy or birth (e.g. *"The nurse just left me in labour... did not call the doctor in time... this led to complications"*).

Overall, the parents' attributions of the initial cause revealed unresolved emotions of anger, guilt and disappointment surrounding the diagnosis of the established disability. These emotions made it difficult for parents to accept the child's established disability, and to move forward with the effective management of the associated challenges (e.g. the child's communication disability). In this study, the intensity of the parents' negative emotions was observed to be high, irrespective of the time period following the diagnosis. Barnett, Clements,

Kaplan-Estrin, McCaskill, Hunt, Butler, et al., (2006) indicated that while elements of unresolved emotions are apparent in most parents, even over a long time period, support should gradually facilitate positive adaptation over time. Literature indicated though, that the specific time period for this to occur would vary for parents due to factors such as the nature and severity of the disability, and their personal and economic resources to access support (Turnbull et al. 1993; Sloper, 1999; Barnett et al., 2006; Neely-Barnes & Dia, 2008). In this study, the period post diagnosis was greater than that of one year for 91% of parents, while there were only three parents (9%) whose children's established disabilities were diagnosed within three months of the study commencing. During Day 1 of training, most parents indicated that it was the first time that they were given an opportunity to talk about their feelings regarding their child's established disabilities. Many parents cried as they shared their experiences and listened to those of the other mothers. The parents' reactions clearly showed that they were still deeply traumatised by their perceptions of the initial cause of the children's established disabilities. In the context of these findings, the parents' ratings of their mental health as good to excellent in both groups at pre-training may be attributed to the Hawthorne effect (McMillan & Schumacher, 2010); or to cultural values and practices that guided care-giving. In their critical review of the burden of care-giving in low- and middle-income countries, Thrush and Hyder (2014) found that care-givers sometimes denied that care-giving had negative social outcomes. This finding was attributed to culturally influenced perceptions of the role of the caregiver, or to the practice of shared responsibilities of care-giving among adults in the family or community, which decreased the burden on primary caregivers. Therefore, the parents' negative reactions regarding causal attributions may not be accurately reflected in their rating of their mental health. Measures of parents' mental health thus needed to be more sensitive in establishing their perceptions of the initial cause of the children's disabilities; and more cognisant of the impact that cultural perceptions of care-giving had on the parents' responses.

The attribution of blame to medical personnel was noted largely in the parents' of children diagnosed with cerebral palsy. It was the primary diagnosis of the majority of the children in this study (approximately 47% of the children in each group - Table 15), and therefore similar to the South African study by Saloojee et al., (2007). Some of the parents had reported their complaints to hospital authorities, but poor follow-up appeared to increase the parents' negative emotional experiences. Pepper and Slabbert (2011) reported a significant

increase in claims for medical negligence in South Africa as both legislation to protect consumers, and patients' knowledge of their rights improved (e.g. Consumer Protection Act of 2008). Obstetrics and gynaecology were the specialities with the highest claims, and infant diagnosis of cerebral palsy at birth was one of the reasons proposed (Pepper & Slabbert, 2011). The findings in the current study suggested that the parents did not possess the knowledge and/or financial resources to address their concerns through the litigation route. Affleck and Tennen (1993) cautioned that parents' attributions of blame on professionals compounded the coping process as it raised questions about the professionals' competence, trustworthiness and benevolence. These negative perceptions could have a detrimental effect on parent-professional collaboration and parents' help-seeking in ECCI, and ECI broadly. This finding was very relevant and highlighted the urgent need for hospital authorities to support parents in addressing their complaints fully at an early stage, in view of its significance in facilitating parents' positive functioning in the long-term. It was also crucial that SLTs and other ECI professionals supported parents by being knowledgeable about policies and procedures from the country's National Department of Health, and monitoring processes until the desired outcomes were achieved. The significance of an integrated framework for ECI and family support to achieve successful outcomes was evident. The findings highlighted the critical need thereof in challenging contexts, such as South Africa (Sloper, 1999; Dunst, 2004; UNICEF, 2005; NPC, 2011; DSD, DWCPD & UNICEF, 2012; Samuels et al., 2012).

The parents' attributions of the *maintaining cause* of the child's communication disability assessed whether the parents looked beyond stable factors (e.g. the child's established disability) and identified unstable factors in the context or task that hindered the child's capacity to communicate effectively. The parent responses in both groups ranged from uncertainty (e.g. "I'm not sure,") to factors internal to the child that were not amenable to treatment (e.g. established disability - "The cerebral palsy," or "He is autistic,"). This finding again highlighted the parents' difficulty in moving beyond the child's established disability. Their acceptance of the established disability would enable them to focus on unstable personal and environmental factors that could be altered during ECCI to enhance the child's communication (Sameroff & Fiese, 2000; Neely-Barnes & Dia, 2008; Wegner & Rhoda, 2015). The fact that the parents did not consider unstable factors emphasised the critical need for them to be informed about the transactional context of causation (Sameroff & Fiese, 2000). The information would broaden the

parents' perspective on achieving positive outcomes, within the context of the child's established disabilities. They would therefore remain hopeful instead of anxious, which would facilitate their creativity in generating alternate solutions for problems that they encountered during parenting (D'Zurilla & Nezu, 2010). Research highlighted the important role that hope played in caregivers' positive adjustment in caring for children and adults with disabilities, particularly in increasing agency thinking (i.e., a determination to seek solutions for difficulties encountered) (Horton & Wallander, 2001; Snyder, Rand & Sigmon, 2002; Madan & Pakenham, 2013). These research findings advocated for the inclusion of hope as a target for intervention.

The parents' pre-training attributions of the initial and maintaining causes of their children's moderate to severe communication disabilities suggested that the majority of parents in the study experienced difficulty in accepting the children's established disabilities. The parents' preoccupation with negative emotions surrounding the diagnosis of established disabilities, and their global pessimistic perceptions about the permanence of the established disability on outcomes, demonstrated signs of negative adaptation and functioning (Barnett et al., 2003; Neely-Barnes & Dia, 2008). The subsequent effect on their decision to access or maintain ECCI or not was likely to be negative, in line with research evident in the literature (D'Zurilla & Nezu, 1999, 2010; Neely-Barnes & Dia, 2008; Wegner & Rhoda, 2015). Support for this was also evident in the response of one parent who questioned the viability of accessing further intervention for her child, who was diagnosed recently (e.g. *"What's the use of treatment? The doctor said that she will be slow in learning. I must just accept.... and leave her alone...it will be less problems for me,"*). The parents' negative perceptions of the established disabilities were also likely to lower their expectations of ECCI outcomes, which influenced the nature of the help that would be requested during problem definition, if ECCI was accessed (McConkey, 1995; Neely-Barnes & Dia, 2008; Wegner & Rhoda, 2015). This issue is discussed in more detail in Section 5.3.2.

The findings of the recent systematic review of the generic and special needs of children with disabilities living in poverty settings in low-and middle-income countries indicated that the issues that precipitated parents' negative orientations towards disability continued to challenge parents in these contexts (Lygnegård et al., 2013). The review highlighted that caregivers' limited knowledge about the causes and permanence of the disability delayed their efforts in seeking the assistance of health care services. The study by Maloni et al., (2010) was cited where

Bangladesh parents believed that the child's disability was temporary, and where they continued to seek treatments that would "cure" the child. Therefore, parents' pre-training orientations suggested that even if parents did initiate help-seeking, their orientations could be insufficient to maintain help-seeking efforts in the long-term, especially when problems encountered become more challenging as the child developed (Singer & Irvin, 1989; Rossetti, 2001; Heller, 1993; Neely-Barnes & Dia, 2008; Wegner & Rhoda, 2015). The findings emphasised the critical need for parental support in problem orientation immediately following the birth and diagnosis of established disability. Support would enable parents to adopt causal attributions that facilitated positive functioning in the long-term, especially with respect to initiating and sustaining help-seeking in ECCL.

***Review of key findings at post-training:*** The parents' attributions of the *initial cause* of the child's communication disability were categorised as: (i) factors beyond anyone's control (thus nobody to blame); (ii) actions of the parents or others, but parents had accepted or were in the process of accepting the outcome and moving forward; and (iii) parents were unsure (reflecting confusion). In comparison to pre-training responses, the parents' post-training responses reflected that the training had initiated the following changes: (i) altered negative pre-training attributions about initial cause of disability, and (ii) helped the parents to progress toward accepting the initial cause and moving forward to support the child (e.g. *"The nurses were negligent... but I don't want to keep thinking about it... My child needs help now... I need to see how to help him,"*). There was a statistically significant shift between pre- and post-training scores regarding the parents' attribution of the *maintaining cause* of the child's communication disability. Their focus shifted from the stable established disability that could not be altered, to unstable personal and environmental factors that could be altered through ECCL to enhance the child's communication (Sameroff & Fiese, 2000; Neely-Barnes & Dia, 2008). For example, *"I'm scared to let him play with other children...They may tease him about his problems...but I see I'm not helping him"*. Finally, the parents' confidence in asking family and friends for help increased, and their appraisal of the child's communication disability transitioned from "Slightly stressful but also a challenge," at pre-training, to "A positive experience that I can benefit from," at post-training (Table 24). These positive training outcomes are reviewed in relation to two factors: (i) the training programme, and (ii) the theoretical framework of problem orientation proposed in the study.

***Review of positive findings in relation to the training programme:*** The innovative combination of the training programme aims, philosophy, structure, content and training strategies, as described in Section 3.4.1.2 and Appendix U, played a critical role in facilitating positive outcomes *overall in the parents' problem orientation and definition*. While the training outcomes could be explained as a novelty effect since the parents were exposed to experiences that were different from their daily care-giving routine (McMillan & Schumacher, 2010), this effect alone is insufficient in explaining the specific pattern of the post-training results (i.e., the differential effects on the five dimensions of problem orientation, and between problem orientation and problem definition). The following training issues were identified as instrumental in achieving the positive outcomes in the parents' problem orientation *and* definition.

***Novel combination of theoretical support:*** At the broadest level, the novel combination of theoretical support from the fields of ECI, ECCI, psychology and teaching and learning (Table 11; Appendix Q) provided a strong basis to plan, implement and evaluate the change process that training precipitated. The training was specifically developed for parents who came from a diverse socio-cultural, economic and education background in South Africa. Findings from the focus groups with parents and SLTs (Table 4; Appendices D and F); Pilot study 4, which assessed the complete research process (Section 3.4.1.3); and the pre-training interview schedule were used to tailor the training to meet the particular needs of the parents in this study, to facilitate positive problem orientation and problem definition. Theoretical principles that were drawn from the different theories were used to guide training. The following principles were instrumental in achieving positive outcomes: capacity building through parent support; a structured approach to promote change; and specific training approaches and methods to facilitate change during the teaching and learning process (Table 11 and Figure Q1).

***Theoretical principles that guided training:*** The current social approach that guided practice in ECCI emphasised parent and family support as the principle means of strengthening children's functioning (Dunst, 2004; Trivette & Dunst, 2005). This emphasis required SLTs to use different theories to facilitate parental support. This study focused on building the capacity of parents to seek help from ECCI for problems experienced in parenting young children with moderate to severe communication disabilities, secondary to established disabilities. The integrated model of ECI and family support (Dunst, 2004) was therefore used as the overall

theoretical framework because it encompassed a capacity-building paradigm, and outlined the five principles that underscored parent-training in this study (i.e. promotion, empowerment, strengths-based, resource-based, and family-centered help-giving). Application of the principles in the study is outlined in Appendix Q, and is further discussed in this review of the study's positive training outcomes. From the field of psychology, the theory of social problem solving was used to operationalise the concept of parents' help-seeking in ECCI. The first two stages of problem orientation and problem definition were used to facilitate parents' capacity to access help (Table 1). The authentic curriculum-based approach in ECI (Bagnato et al., 1997; Bagnato, 2007; Bricker & Cripe, 1992) was then used to identify parents' underlying values, beliefs and skills which underpinned their orientation to, and definition of problems when accessing ECCI (Table 5). This information enabled SLTs to identify specific competencies and the associated content for training. Two core values were emphasised during POD training, based on the information obtained from the focus groups, Pilot study 4 and the pre-training interviews. The acknowledgement and acceptance of children with disabilities as important members of the family, who needed love and nurturing to achieve their full developmental potential within the limits imposed by the established disabilities (Rossetti, 2001; Saloojee, 2006; Neely-Barnes & Dia, 2008); and the collaborative problem-solving partnership as the central medium in ECCI that utilised the expertise of the parent and the professional to facilitate positive outcomes for the child (Dunst et al., 1994a; Granlund et al., 2005). In addition, the dimensions of problem attribution, personal control and problem appraisal were emphasised. Although not comprehensive, the parent support studies that are reviewed in Table 2, also denoted that one or more of the three dimensions were prioritised during training.

Change management theories from the field of psychology were used to structure training so that the parents were supported systematically, at the individual and group levels, through emotional, social, cognitive and behavioural processes. The processes motivated parents to initiate, to maintain and to evaluate two aspects: the adoption of positive orientations towards children's established and communication disabilities; and the parents' effective implementation of their role as help-seekers when they communicated their problems and needs to SLTs during ECCI (Bandura, 1998, 2001; Schwarzer, 1999; Crookes, 1998; Barnett et al., 2003; Neely-Barnes & Dia, 2008).

*Operationalisation of training principles:* The theoretical principles described were operationalised during training through two central techniques. Firstly, an empowering *parent-professional relationship* was established using relational and participatory practices of family-centered help-giving (Dunst et al., 2002; Finfgeld, 2004; Nelson et al., 2001). Participatory practices were emphasised as the research showed direct effects on parent self-efficacy beliefs and well-being (Trivette et al., 2010). Secondly, to initiate and maintain change, different training methods were selected to influence emotional, social, cognitive and behavioural processes. Table 26 briefly reviews how the training principles were hypothesised to have influenced statistically significant outcomes in the three dimensions of problem attribution, personal control and problem appraisal. The table focuses on training methods that were considered influential in achieving positive outcomes for the parents in this study, particularly at the motivation and initiation phases.

Table 26

*Influence of training principles on the parents' positive problem orientation outcomes and the implications for parental support in ECCI*

<i>Summary of training principles</i> <b>Family-centered, collaborative parent-professional partnership</b>				
<b>Training phase</b>	<b>Training process</b>	<b>Training methods</b>	<b>Influence in facilitating positive problem orientation outcomes &amp; implication for parent support</b>	<b>Change facilitated in:</b>
<b>Strengthen motivation to change</b>	Social	Parents sharing individual parenting experiences	- Parents shared positive and negative parenting experiences. <i>Implication: SLT must be skilled in family-centred help-giving</i>	Problem appraisal
	Emotional	Cognitive re-framing	- Many parents cried as they spoke or listened to each other. Facilitated emotional bonding among parents when they recognised similarities in experiences and challenges - they were not alone.	
	Cognitive	Learner input	- Parent stories reflected different levels of coping due to variations in parenting experience and access to ECCI. Those displaying positive coping tendencies demonstrated that <i>it was possible</i> to manage the challenges, with support from ECCI and their social network. <i>Implication: Include parents who show positive orientations in training</i>	

<i>Summary of training principles</i>				
<b>Family-centered, collaborative parent-professional partnership</b>				
<b>Training phase</b>	<b>Training process</b>	<b>Training methods</b>	<b>Influence in facilitating positive problem orientation outcomes &amp; implication for parent support</b>	<b>Change facilitated in:</b>
<b>Initiate change</b>	Emotional	Parent stories	<p>- Parents compared their challenges to those of other mothers and people with other challenges. Realised that some confronted challenges which were more severe in comparison to their own, which promoted cognitive reframing of own challenges.</p> <p><i>Implication: normalise problems</i></p> <p>- Recognition of common challenges irrespective of the types and severity of child's established disability, and the background of parent (race, language and culture): negative reaction of the community towards children with disabilities and families, attribution of blame to the mother; limited support in managing care-giving demands from husbands.</p> <p>- Initiated support among parents, especially between emotionally strong and emotionally weak parents. This was strengthened during tea-breaks.</p> <p>- Parents related easily to the concept of "warrior mum", because it denoted strength in the South African Black and Indian culture. They identified with the image of being a strong and assertive advocate who accessed help and managed parenting challenges in raising children with disabilities.</p> <p>- Enabled parents to understand the inter-play between genetic and environmental factors in causing disability and promoting outcomes. Initiated cognitive re-framing. Provided mothers with information to challenge negative cultural beliefs and practices.</p> <p>- Mothers who were coping positively shared successful strategies for managing challenges. Role models and strategies were appropriate for parents' demographic backgrounds.</p> <p><i>Implication: Select culturally relevant training methods</i></p>	<p>Problem appraisal</p> <p>Personal control (self-efficacy and outcome expectation)</p>
	Social	Cognitive re-framing		
	Cognitive	Modeling Video "Are you going to finish strong?" (Nick Vujicic)		
		Personal story of a cancer survivor		
		Image-making (warrior mum) Guided reflection on homework task		
		Lectures (transactional regulation theory of causation)		
		Problem solving group discussions to manage the parent needs identified during personal stories, shared on Day 1 Modeling Learner input Video 1-confident parent's story Gratitude journal Inspirational		<p>Problem attribution (initial and maintaining causes)</p>
			- Daily entries helped parents shift focus from negative to positive	

<i>Summary of training principles</i>				
<b>Family-centered, collaborative parent-professional partnership</b>				
<b>Training phase</b>	<b>Training process</b>	<b>Training methods</b>	<b>Influence in facilitating positive problem orientation outcomes &amp; implication for parent support</b>	<b>Change facilitated in:</b>
		slideshows	experiences. Developed skill in recognising and acknowledging positive changes in the child's behaviour, no matter how small.	
	Behaviour	Introducing their children to mothers in the group through photographs of the child Day 4	- Normalised parenting behaviour, acknowledged children and their accomplishments. Developed parents' confidence to talk about children's positive attributes. <i>Implication: normalise parent role</i>	
<b>Maintain change</b>	Cognitive Social	Gratitude journal Tea breaks, group discussions, train resident SLT	Daily journal entries, social relationships and formal support were important methods to maintain positive changes after training.	Problem appraisal Self-efficacy

*Training process and training methods:* The review and implications listed in Table 26 suggested that six factors, specific to the training process and methods, were influential in facilitating positive orientations in the parents' personal control (i.e. self-efficacy), attribution and appraisal of problems. These factors have important implications for the education and training of parents and SLTs' to achieve effective parent training. The *first factor* was the use of family-centred, help-giving practices, and its influence as the fundamental medium for change. Findings indicated that family-centred, help-giving practices were successful in creating a comfortable and safe training environment which enabled the parents to engage freely in discussing the positive and negative aspects of their parenting experiences on Day 1. It also promoted the parents' active participation in the different training methods that were used to motivate and initiate change. Training success was evident on Day 4 when parents spoke confidently and proudly about their children with disabilities. Subjective evaluation during training also demonstrated positive changes in the parents' progress through the empowerment process over the four days of training. These positive outcomes are attributed largely to the use of participatory, help-giving practices (Dunst et al., 2002; Dunst et al., 2007). As described in Finfgeld's (2004) guidelines, parents' increasing skills in participating, choosing, supporting and negotiating during group discussions demonstrated their growth in the empowerment process. The positive outcomes highlighted the significance of SLTs' therapeutic skills in creating and

maintaining the fundamental medium for change, namely, an enabling and empowering learning environment (Dunst, 2002; Dunst, 2004; Dunst et al., 2007; Seligman, 2002; D’Zurilla & Nezu, 1999, 2010). Although the trainer’s clinical and teaching experience in an academic context could have contributed to the skilled use of the methods during training (Crookes, 1998; D’Zurilla & Nezu, 1999), the inclusion of family-centered practice, counseling, and the principles of education and training in the scope of practice of the profession of Speech-Language Pathology underscores the capacity of all therapists to achieve similar training outcomes both internationally and nationally, with self-reflective practice (American Speech-Language-Hearing Association, 2007; Department of Health, in press; Dunst & Trivette, 2009).

The *second influential factor* was the alignment of training methods with the sequence in which the training process occurred. The training process emphasised the social, emotional, and cognitive levels initially to strengthen the parents’ motivation to change, and later, to support their initiation and maintenance of the change process. These changes were critical in achieving positive changes at the behavioural level (Peter, 1992; Bandura, 2001; D’Zurilla & Nezu, 1999; 2010; Dunst & Trivette, 2009). For example, the parents shared their individual stories with the group *at a social level* on Day 1. The stories created opportunities to initiate, strengthen and maintain the relationship bonds among parents who shared similar challenges. It was a powerful method to motivate and initiate change *at an emotional level* because it provided a platform for the parents to voice their positive *and* negative feelings, and to have these feelings acknowledged without judgement by the other participants (Turnbull, et.al., 1993; Seligman, 2002; Niederhoffer & Pennebaker, 2002; Woods & Lindeman, 2008). The content of the parents’ stories also highlighted the key dimensions that needed greater attention during training. In this case, the content supported the results of the focus group with parents, Pilot study 4, and pre-training findings in its focus on parenting issues that were relevant to the dimensions of problem appraisal, problem attribution and personal control (self-efficacy). The parents who exhibited positive orientation tendencies reached out and offered emotional support to those who did not. The literature also indicated that parents were more receptive to receiving support from the other parents confronting similar circumstances (Barnett, et.al., 2003; Turnbull, et.al., 1993; Neely-Barnes & Dia, 2008; Samuels et al., 2012). *At a cognitive level*, training methods such as image-making, cognitive reframing and lectures, were crucial in destabilising cultural beliefs, values and perceptions that hindered the parents’ positive functioning; before positive changes could

occur at a *behavioural level* (e.g. introducing their child to the other parents) (Peter, 1992). These cultural beliefs, values and perceptions were discussed earlier in relation to the initial and maintaining causes of disability, outcome expectancies, role of the parent as advocate and change agent, and the benefits of ECCI. For example, lectures provided information that challenged parents' current beliefs and practices, and initiated the process of cognitive reframing (e.g. transactional regulation of causation, specifically for identifying unstable, maintaining causes of disability; and the role of parent as change agent and advocate) (D'Zurilla & Nezu, 1999; Dunst & Trivette, 2009).

The *third influential factor* was the emphasis placed on the “normality” of problems experienced in everyday life (D'Zurilla & Nezu, 1999, 2010). Particular training choices and methods therefore enabled the parents to view their problems in perspective to those of others. This was important as it facilitated parent adaptation from two points: (i) the adoption of a sense of agency rather than victimhood (Seligman, 2002), and (ii) the adoption of the cognitive adaptation strategy of self-enhancement, after comparing the severity of their own problems to those of other individuals and parents (Taylor, 1983). For example, the experimental group included parents of children with a range of established disabilities; and training videos and presentations included individuals from diverse racial, linguistic and cultural backgrounds, who modeled positive coping strategies in the face of very challenging personal circumstances (e.g. young White man who was born without arms and legs, and an older Indian mother diagnosed with cancer).

The inclusion of training methods which were suitable for the specific socio-cultural needs of the demographic profile of the families within this study was the *fifth influential factor*. Cross-cultural research emphasised the need for interventions to include the values and practices of a culture into interventions in order to be relevant and sustainable (Keller, Coe & Moore, 2014; Kisanji, 1995; McConkey, 1995; Harry, 2002; Neely-Barnes & Dia, 2008; Samuels et al., 2012). The parents in the experimental group who showed positive coping tendencies at pre-training proved to be invaluable during training, as they were from the same language, culture and racial background as the participants in the study. The training videos (Appendix T) also included parents from the same demographic profile. The image of parents as “warrior mums” worked very well because South African Indian and Black parents were familiar with the traditional ideology that underpinned the concept. They therefore related to the implied

characteristics required. The parents who coped positively in the videos and in the group became role models for the other parents who were not coping as well. The use of problem-solving as a coping strategy was also demonstrated practically to parents in order to enable them to use the skills to access social support when they needed it. For example, during group discussions, the parents who displayed positive orientations and had more parenting experience shared strategies that they successfully used to manage problems that many of the other mothers complained about during their personal stories (e.g. blame attributed to the mother, limited support from husbands). However, the parents in the study highlighted the need for the greater involvement of fathers during training, so that challenging issues could be discussed in a supportive environment (especially those relating to traditional beliefs and practices). In a meta-analysis of father-involvement in parent training, Lundahl, Tollefson, Risser and Lovejoy (2009) indicated that the inclusion of fathers promoted better parenting practices and positive changes in the child. Similar to previous studies that are reviewed in Table 2, the majority of the participants in this study were mothers (97%), with only one father participating in the control group (Table 15). It was therefore evident that marital counseling was an important component to include in empowerment-based support for two reasons: to ensure that training outcomes were supported in the marital relationship, and to prevent the adverse effects that training outcomes could generate for mothers especially (e.g. enhanced self-efficacy that triggered domestic violence) (Sloper, 1999; Neely-Barnes & Dia, 2008).

Finally, the inclusion of typical parenting behaviours during training was the *sixth influential factor*. Training emphasised the role of the parent and not the child's disability, as evident in studies of parents who coped positively (Appendix A). Pre-training assessments and the parents' stories on Day 1 indicated that they generally avoided talking about their children in social contexts. The method enabled them to move past the stigma of the disability, to focus on other positive characteristics of the child, and to relate to the child in the manner in which they related to the other children within the family. For example, on Day 4 the parents introduced their children to each other with a photograph and the brief information that they typically shared with others (e.g. child's name, age, personality and hobbies).

The six factors discussed highlighted key theoretical principles that were successful in meeting the unique needs of the parents in the experimental group. The review indicated that SLTs need to be knowledgeable and skilled in designing educational curriculums for parent

training, and in implementing them effectively. While these issues are included in SLTs' undergraduate training (American Speech-Language-Hearing Association, 2007; Department of Health & Health Professions Council of South Africa, 2012); the depth of training may be inadequate to facilitate competence at the detailed level required in this study. The need for SLTs to receive additional support is evident.

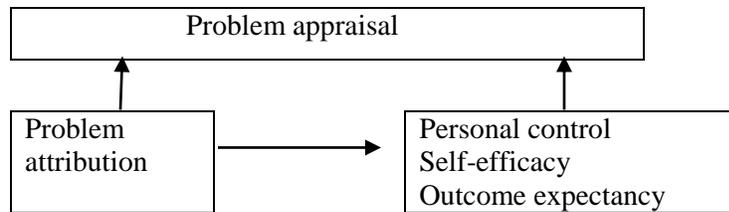
*Training sequence:* The training sequence commenced with problem orientation and proceeded to problem definition, as is stated in the aim and training plan in Appendix U, and motivated for in Section 3.4.1.2. D'Zurilla & Nezu (1999) highlighted that the two components of problem orientation and problem solving are only partially independent (Section 2.3.2). Since the problem orientation and problem definition variables were trained individually, but evaluated *after* training was completed for both variables, an interaction effect between the two variables is probable, and thus acknowledged (McMillan and Schumacher, 2010; D'Zurilla & Nezu, 1999). The post-training outcomes measured in each variable are therefore likely to include the interactions and combined effects of training in both variables. This study used a problem-solving perspective to support parents' help-seeking in ECCI. Help-seeking was operationalised using the first two stages of the model of social problem solving, namely, problem orientation and problem definition. The precise contribution of each variable to the final outcome was not considered crucial at this initial research stage. Instead, the key focus was to establish whether the variables provided a relevant framework for training to facilitate parents' *motivation* to access ECCI, and parents' *communication of problems and needs* during intervention to access the help that they required. The findings for both aspects were positive.

The review of statistically-significant findings in problem orientation and the parents' favourable evaluation of the training programme (Table AH8) suggested that a comprehensive set of issues related to the aims, philosophy, content, structure and process, trainer, and environment of the training programme played important roles in influencing the study's positive findings in items in the dimensions of problem attribution, problem appraisal and personal control (self-efficacy component). This study makes a crucial contribution in identifying a specific mix of training components that are successful in facilitating positive orientations in South African parents from diverse linguistic and cultural backgrounds, and who are living primarily in lower socioeconomic conditions (Table 15). The positive findings will motivate

SLTs to ensure that future parent support programmes in ECCI include the neglected yet crucial area of parents' orientation to children's communication and established disabilities.

***Review of positive findings in relation to the theoretical framework of problem orientation proposed in this study:*** Statistically significant findings in items in three of the five dimensions of problem orientation suggested that theoretically, the three dimensions of problem attribution, problem appraisal and personal control could be interrelated. Interpretation of training outcomes from this stance suggested that the training influenced a common factor underlying the three dimensions of problem orientation. Consideration of problem orientation from the perspective of a multidimensional construct (Section 2.3.1), implied a “factor view” of the relationship between the three dimensions and overall problem orientation construct, *at the broadest level* (Law & Wong, 1999; Wong et al., 2008). The “factor view” suggested that problem orientation may characterise a latent construct with the five dimensions presenting different manifestations of problem orientation (Law & Wong, 1999). From this perspective, the study's post-training findings make an important theoretical contribution to the field of ECCI because it suggests that three of the five dimensions may reflect a core set to focus on during training to facilitate parents' positive orientations.

*At a more specific level*, pre- and post-training findings alluded to a particular trajectory in the nature of the relationship among the three dimensions. This trajectory could explain the mechanisms that contributed to positive changes in the parents' problem orientations at post-training. It is suggested that the positive shifts noted in the dimension of problem attribution (specifically the items related to the maintaining cause of disability, followed by the initial cause), may have played an important role in facilitating positive changes in the dimension of personal control (self-efficacy component, where the parents felt more confident to approach family and friends for help). Positive changes in both these dimensions may have influenced the dimension of problem appraisal (i.e. perceiving disability as a challenge instead of a threat). Figure 6 is a schematic presentation of the interrelationship among the three dimensions, as hypothesised from the study's main findings following POD training.



*Figure 6.* Schematic presentation of the interrelationship hypothesised in the dimensions of problem attribution, personal control and problem appraisal for the parents’ of children with moderate to severe communication disabilities that is secondary to established disabilities.

The interrelationship that is hypothesised among the three dimensions is supported by the theory of cognitive adaptation (Taylor, 1983) and the theory of successful coping (Antonovsky, 1993), as discussed in Section 2.3.1. The importance of problem attribution as the dimension that *initiated* the process of successful coping and adaptation was highlighted in both theories, since attribution enabled individuals to understand the mechanics of the problem (Antonovsky, 1993, Taylor, 1983). In so doing, it is hypothesised that the dimension of personal control enabled the identification of aspects of the problem that could and could not be controlled (i.e. unstable versus stable factors, respectively), thereby allowing focus to shift to the unstable aspects that could be controlled (D’Zurilla & Nezu, 1999, 2010). In this study, the concept of problem attribution was analysed theoretically in ECI as the initial and maintaining causes of the child’s communication disability (Granlund et al., 2005), and the breakdown corresponded with the framework that was used in the field of psychology, namely; stable and unstable attributions (Section 2.3.1.2). The study findings suggested that parents’ understanding of the maintaining cause of the problem (unstable factor) was possibly the *crucial activator in initiating the shift toward positive problem orientation* because it instilled hope for achieving better outcomes. In this study, information on the transactional context of causation was therefore a crucial cognitive training method that could enhance parents’ sense of hope. Parents were likely to access and persist with ECCI for children with moderate to severe communication disabilities, which were secondary to established disabilities. In addition, the study’s findings foregrounded the central role that the parents’ cultural interpretations of disability played at the level of maintaining and initiating causes, specifically for South African Black and Indian parents. This finding was supported in the international and national literature reviewed in Section 2.3.1.2, and it

emphasised the need to identify and support parents' adoption of cultural interpretations of disability that facilitated their positive orientations to parenting children with disabilities. In this way, their motivation to access help from family and friends (informal resources), and ECCI (formal resources) could be strengthened, as is evident at the post-training stage (Table 24). Specific training issues that were found to be relevant in this regard were discussed earlier (e.g. knowledge about the transactional view of causality).

The statistically significant findings in items in the three dimensions of problem orientation had important implications for SLTs' support of parents' help-seeking in ECCI. Firstly, the findings suggested that the three core dimensions of problem attribution, problem appraisal and personal control played a critical role in facilitating parents' positive functioning as help-seekers in ECCI. While it was important that SLTs assessed parents' orientations in the five dimensions, it was vital that the three dimensions were prioritised when parent training in problem orientation was planned and implemented. Secondly, the findings suggested that parents' problem attribution was the crucial initiator of their positive functioning in the remaining two dimensions. It was therefore imperative for SLTs to ensure that parents' problem attributions received precedence during training, especially their attributions of the maintaining and initial causes of the children's established and communication disabilities. Negative attributions needed to be identified as early as possible following diagnosis, as these were central in hindering parents' motivation to seek and sustain help from ECCI, particularly in parents from diverse and traditional cultural and religious backgrounds (Harry, 2002; Saloojee et al., 2006; Neely-Barnes & Dia, 2008; Wegner & Rhoda, 2015). Collaboration with other team members, especially the psychologist, may be required to facilitate parents' positive coping and functioning post-diagnosis if they demonstrated severe difficulties in accepting the diagnoses and moving forward (Rossetti, 2001; Barnett et al., 2003; Neely-Barnes & Dia, 2008). Speech-language therapists needed to prioritise parent support because the parents' and families' positive functioning as decision-makers and help-seekers were essential to achieve effective and sustainable ECCI outcomes (Dunst, 2004; Dunst et al., 2007). The need for SLTs to be skilled in supporting *families'* positive functioning had important implications for education and training programmes at both undergraduate and postgraduate levels. The Health Professions Council of South Africa (HPCSA), through the Professional Board for Speech-Language Therapy, needed to ensure that the psychology and clinical modules in the undergraduate curriculum equipped

students with the requisite knowledge, skills and attitudes required to assess and support parents and families to function positively as help-seekers in ECCI. Similarly at a postgraduate or professional level, the HPCSA needed to ensure that Continuing Professional Development programmes extended SLTs' competence from that of novice to expert.

### ***5.2.1.2 Review and implications of non-significant findings in problem orientation***

A review of the pre- and post-training mean scores of the nine items that were not statistically significant (Tables 22 and 24) indicated that pre-training mean scores were high in the control and experimental groups (i.e.,  $\bar{X} > 3.00$ ). This finding reflected that the parents' problem orientations in the dimensions of problem perception, personal control (outcome expectancy and aspects of self-efficacy regarding confidence in their own knowledge and skills, and approaching professionals for help) and commitment of time and effort were already in the positive range at pre-training. The restricted range in pre- and post-training mean scores contributed to a ceiling effect and explained the non-significant differences for these items, in the between-group and within-group analyses (McMillan & Schumacher, 2010; Leedy & Ormrod, 2013). The ceiling effect also explained why statistically significant effects of training were not maintained from the between-group analysis to the within-group analysis in the three items located in the dimensions of problem perception (i.e., parents' recognition of the need for communication intervention) and personal control (i.e., parents' expected outcome regarding the child's communication, and their confidence in using their own knowledge and skills to help their child) (Table 24). A review of the within-group analysis for these three items in Table 24 suggested that while the mean scores increased from pre- to post-training in the experimental group, the within-group changes were not large enough to maintain statistical significance.

The parents' generally positive orientations at pre-training were supported by the descriptive information on participants listed in Table 15. While more than 80% of the parents in both groups rated their mental health as good to excellent; SLTs' rated 53.33% of the parents in the experimental group and 63.16% of the parents in the control group as coping positively in parenting children with disabilities. Two factors that could explain why the parents' problem orientations were generally positive at pre-training included the study's participant selection criteria and internal validity.

The experimental and control groups were functionally equivalent (Section 4.2.3). However, the participant selection criteria offered two explanations for the parents' problem orientations being largely in the positive range at pre-training. The explanations related to the duration of the parents' attendance at ECCI, and the use of volunteers as participants. The study participants included the parents of children who had received ECCI services for a time period of between 0-12 months. Personal communication with the resident SLTs indicated that the parents who met the 0-3 month ECCI exposure range that was set initially, were reluctant to participate as they were trying to cope with the diagnoses (i.e., established and communication disabilities). Results indicated that the majority of the parents in the experimental and control groups had received ECCI for between 6-12 months, with only three parents in the 0-3 month range. Parents' positive orientations at pre-training could thus reflect the outcomes of the ECCI that was received prior to the training.

Personal communication with SLTs indicated that ECCI focused primarily on enhancing parents' management of communication and feeding difficulties. In the absence of data that reflected what the parents' orientations were at the onset of ECCI, it would appear that ECCI and the exposure to parent-group interventions could promote parents' positive orientations in items in the dimensions of problem perception (e.g. recognising and seeking intervention for communication and feeding problems), personal control (e.g. learning and using relevant treatment strategies), problem appraisal (perceiving the disability as a challenge after engaging with mothers who had more experience), and commitment of time and effort (e.g. feeling motivated to implement home programmes). In many of the intervention studies reviewed in Table 2, parents commented on the positive benefits that they gained from informal interactions with other parents who had children with similar disabilities. Studies indicated that the social dimensions of the programmes were often given secondary attention, but these could play an important role in achieving positive outcomes. Prins, Toso and Schafft (2009) examined the importance of the social interaction and the support that women in poverty derived from adult education and family literacy programmes, and concluded that both factors enhanced the women's psychosocial well-being. Therefore, while the parents in this study may have benefitted similarly from the social dimensions of ECCI generally, pre-training results indicated that these benefits appeared insufficient in enabling them to acquire completely positive orientations ( $\bar{X} = 4.00$ ) in items *across the five dimensions of problem orientation* (Table 1). Table 24 indicates

that at pre-training, the parents in both groups showed completely positive orientation in only one item concerning their commitment of effort to help their child. At post-training, however, completely positive orientations were evident in six items in the experimental group, and there were no changes in the control group. With respect to the nine non-significant items, Table 22 reflects positive shifts in all items from pre-training to post-training. This finding indicated that despite the non-significant changes in findings, the parents benefited from the training in problem orientation.

The second explanation for the parents' generally positive orientations at pre-training related to the selection of parent volunteers, as this criterion was likely to appeal to the parents who coped positively. It is unlikely that parents who had negative orientations would volunteer to participate in the study. Negative orientations were often evident immediately after the diagnosis of the children's established disabilities (Rossetti, 2001; Herbst & Maree, 2006), and the small number of parents who volunteered to participate in this study during this early period post-diagnosis, supported the contention. Finally, despite the precautions taken to minimise the Hawthorne effect during data collection (Section 3.4.2.4.1), its influence could not be ruled out completely, especially in the parents' positive responses about their commitment of time and effort to help their child develop communication skills (Table 24), and their mental health (Table 15). However, descriptive studies on parents of children with disabilities in general have indicated that parents were willing to support their children (Singer and Irvin, 1989; Rossetti, 2001; Neely-Barnes & Dia, 2008).

The study's participant selection criteria may therefore have accounted to some extent for the non-significant effects of training on the parents' problem orientation, notably their access to ECCI. The non-significant findings in problem orientation highlighted important issues for the practice of ECCI. For the parents who accessed ECCI, it established that the benefits of intervention did not empower parents to be effective help-seekers. The parents' largely-positive orientations at pre-training were clearly insufficient for them to sustain their involvement in ECCI when they experienced specific parenting challenges (e.g. negative reactions of the community towards the children's disabilities; dissatisfaction with intervention outcomes). The motivation for this study indicated that many parents simply stopped attending ECCI (Section 1.2). This parental reaction reflected a lack of specific knowledge and skills about the children's established and communication disabilities, which were crucial in motivating parents to persist in

seeking help from ECCI. The non-significant findings also highlighted the need for SLTs to assess parents' problem orientations immediately after diagnoses of the children's established and communication disabilities. Descriptive studies on parents' coping and adaptation to children's disabilities (Section 2.3.1) and the parents' reluctance to participate in this study during the early period post-diagnosis, provided evidence that their problem orientations were in the negative range. The parents' need for support in the non-significant areas of problem perception, personal control and commitment of time and effort, was therefore likely to be greater at diagnosis, when compared to that observed at pre-training when they were accessing ECCI (Table 24).

Overall, the analysis of significant and non-significant findings clearly demonstrated that the parents' problem orientation in three dimensions did not adequately facilitate effective help-seeking in ECCI at pre-training; and that the specific training that was provided in this study was relevant in promoting orientations that underpinned effective help-seeking. Positive training effects were likely to increase if parent training was provided immediately after diagnosis, when the parents' orientation towards disability was most vulnerable. An analysis of the key findings in the parents' definition of problems is presented next.

### **5.2.2 Analysis of key training outcomes in parents' problem definition: implications for parents' help-seeking in ECCI**

Table 23 indicates that the training programme had a statistically significant effect with large effect sizes in the parents' overall problem definition skills, and specifically in the organisation of information and the specificity, concreteness and comprehensiveness of the information provided. The findings implied that the training had a positive effect in enabling the parents to communicate relevant information (i.e., specific, concrete and comprehensive) in an organised manner when defining their problems and needs to SLTs during ECCI (Table AK2). The findings therefore suggested that unlike problem orientation, *all areas of problem definition were vulnerable* and therefore compromised the parents' competence in seeking help effectively from ECCI. Pre-and-post-training outcomes were reviewed to highlight the key issues that influenced problem definition skills for the parents in this study. Clinical and research

implications are discussed for parents' communication of their problems and needs during ECCI, and for the ability of SLTs' to provide ECCI that meets the needs identified.

***Review of key findings at pre-training:*** Table AK4 reveals that the parents in the experimental and control groups displayed poor to moderately poor skills in communicating information in an organised manner to facilitate the SLT's understanding of their problems and needs ( $\bar{X} = 1.87$  to 2.11). The parents also provided information that was of low relevance for planning ECCI that met their needs ( $\bar{X} = 1.51$  to 1.57) as the information was poor in terms of specificity ( $\bar{X} = 1.60$  to 1.68) and concreteness ( $\bar{X} = 1.49$  to 1.63); and low in comprehensiveness ( $\bar{X} = 1.48$ ). They therefore showed poor problem definition skills overall ( $\bar{X} = 1.70$  to 1.85). The findings implied that parents currently had limited competence in the two key areas that facilitated "good" problem definitions for effective ECCI planning. Firstly, the parents described their problems and needs in a poorly organised format, with limited cohesion between the three components (i.e., what is the problem, what is the desired outcome and what prevented attainment of the desired outcome). The finding showed that the parents did not follow a systematic approach when they presented their problems and needs to health professionals. Secondly, parents provided an inadequate amount of relevant information about their problems and needs. The information was not specific and concrete in relation to the ICF categories of body structure and functioning, activity and activity limitations, participation restrictions, and personal and environmental factors (Section 2.3.2.2). Descriptions contained limited examples of the child's communication disability and other associated problems, as experienced in the families' daily activities and routines; and it was not comprehensive to illustrate clearly the onset, development and current status of the communication disability (Section 2.3.2.2). An evaluation of statistically significant inter-rater agreement findings in Table AH3 suggests that while the provision of relevant information was poor overall, the parents gave slightly more specific, concrete and comprehensive information about what their desired intervention outcomes were (i.e., needs), when compared to what the problem and obstacles were. The slightly greater detail that parents provided about their desired outcomes facilitated the raters' ability to evaluate the relevance of parents' information, thereby promoting inter-rater agreement. In contrast, the less detailed information that parents provided about their problems and obstacles hindered the raters' ability to evaluate the relevance of parents' information, and

contributed to statistically significant differences in these ratings (Table AH3). The finding highlights two important aspects. Firstly, it supports the assertion of Björk-Åkesson et al. (1996) in Section 1.2 that during problem definition, parents expressed their needs by describing resources that they require to resolve problems, instead of the problems that the resources were intended for. This finding therefore implies that parents were not aware of: (i) the importance of providing detailed information about their problems and obstacles, *as well as* their needs, and (ii) how the information was used by SLTs to plan effective and sustainable ECCI. Secondly, the statistically significant differences between the two raters implied that the raters may have relied on other clinical resources to evaluate the relevance of the limited information given, for intervention planning. One clinical resource that may explain inter-rater differences may be the level of the raters' clinical experience and expertise in processing and interpreting parents' definitions of problems and needs during ECCI, especially when parents provided limited information. Rater 2 had five years of clinical experience whilst Rater 3 had two years. In studies that explored clinical decision-making between practitioners, clear differences between experienced and beginner practitioners are reported (Carter & Iacono, 2002; Tourmen, 2009; Burger et al., 2010). To illustrate, Tourmen (2009) examined experienced and beginner practitioners' decision-making activities that underpinned their logical choice-making during programme evaluation, and the influence of evaluation theory on those choices. Findings illustrated that experienced evaluators were results orientated as they focussed on the broader goal; they used their theoretical and pragmatic or experiential knowledge (i.e. conceptual resources) in a flexible way to understand the context of the situation, and to anticipate desired outcomes; and they made compromises between prescribed goals and methods in order to achieve the broader goal. In contrast, beginner evaluators were largely influenced by prescribed theory and were method-orientated as they focussed on prescribed goals and methods in an imitative, step by step process; they paid minimal attention to the context, acted in a mechanical way and were mainly concerned with technical matters; and they were unable to anticipate the consequences of their choices (Tourmen, 2009). Application of these findings to the current study would reflect that the more experienced rater (Rater 2) applied theoretical knowledge and clinical experience to the limited information that parents provided in sub-dimensions 1 and 3, and made inferences about the problematic behaviour or situations. The rating agreement between Rater 2 and the researcher provided further support for this contention. The finding

therefore: (i) supports the decision taken in Section 3.4.2.3.3 to resolve discrepancies between the raters by comparison with the researcher's ratings rather than through discussions between the raters, and (ii) provides additional confirmation about the accuracy and reliability of the data.

Although marginal, the inter-rater difference in Table AH4 also suggests concern about the ability of parents to provide operational or concrete information about their problems and needs. The parents provided very little concrete information (i.e., examples taken from their daily activities and routines), in comparison to specific and comprehensive information. Concrete or operational information enabled the SLT to develop an in-depth understanding of problems (D'Zurilla & Nezu, 1999). Again, the difference in the raters' clinical experience may account for differences in inter-rater agreement. When therapists' understanding was compromised by parents' provision of insufficient details, then experienced raters were likely to use their theoretical knowledge and clinical experience to make inferences about the problematic behaviour or situations based on the information provided, and knowledge of the parents' situational context (Tourman, 2009). Findings reflected that Rater 2 may have used theoretical knowledge and clinical experience to infer and derive a better understanding of how the problem presented in the parents' daily life. Again, the similarity in scores between Rater 2 and the researcher provided confirmation of the reliability of the data.

The trends in the parents' problem definition behaviours identified specific gaps in their competence, which hindered their ability to communicate their problems and needs effectively. The results were invaluable as it highlighted problem definition skills that required particular emphasis during parent support.

In response to the open-ended question for parents to communicate their concerns, their typical descriptions at pre-training were: "*My child cries all the time...I don't know what to do,*"; "*My child is not talking...it is difficult...I want him to talk,*" and, "*He won't listen...I need help with his behaviour.*" The information was limited and contributed to SLTs obtaining a generally poor understanding of the parents' problems and needs (Appendix K). Therefore, pre-training results implied that the parents' current definitions of their problems and needs were inadequate to facilitate the planning and implementation of effective, sustainable and versatile ECCI. The results accounted for ECCI not addressing parents' needs, and parents' subsequent dissatisfaction with interventions received (Section 1.2).

The credibility of the findings was also supported by similar outcomes in international research on health literacy. Studies in America and Canada (Section 2.3.2.2) found that irrespective of education and literacy levels, large sections of the population had low health literacy skills, including help-seeking (Wagner et al., 2009; Hentz & Ellis, 2010; Levasseur & Carrier, 2010). In this study, the language and education profiles of the parents were better than those of the majority of South African caregivers of children with disabilities, and the general population (Fair & Louw, 1999; Wasserman et al., 2010; NPC, 2011; Statistics South Africa, 2014a). All of the parents spoke and understood English (Section 3.4.2.1); and the majority had completed high school (80.00% and 47.37% in the experimental and control groups respectively, as evident in Table 15), while some had tertiary education (6.67% and 31.58% respectively, as is recorded in Table 15). The parents' access to ECCI for between 3-12 months was also not relevant in enhancing their knowledge of the children's communication problems, so that they were able to provide relevant information during problem definition. International research and the findings of this study therefore suggested that the parents' poor problem definition skills reflected a global phenomenon (Wagner et al., 2009; Hentz & Ellis, 2010; Levasseur & Carrier, 2010). In relation to the broader concept of health literacy, the findings therefore implied that help-seeking required specialised knowledge and skills which were not provided in academic programmes at schools and tertiary institutions. For the parents of children with established and communication disabilities, it was therefore imperative that SLTs in ECCI programmes supported parents to acquire the specialised knowledge and skills that they needed, in order to communicate their problems and needs effectively when seeking help for the children's communication disabilities.

Additional issues that explained the parents' poor problem definition skills at pre-training included their moderately negative orientations in attributing initial and maintaining causes of the child's communication disabilities (Table AK1); and three factors that parents discussed during POD training. The parents' negative causal attributions contributed to their lower expectations of the children's developmental potential, limited knowledge about ECCI as a resource, and the SLTs' lower rating of the parents' coping skills (Table 15). These outcomes were likely to have a negative effect on the parents' knowledge of the child's communication and other associated problems, and therefore explained their limited ability to provide specific, concrete and comprehensive information about their problems and needs. In addition, the

parents' attribution of blame to medical professionals negatively affected their trust in professionals' competence (Section 5.3.1). Negative perceptions eroded parents' confidence in ECCI as a treatment option, and limited their efforts to provide relevant information for intervention planning. Hence, parent support in acquiring positive orientations towards the child's established disability in particular, was important to facilitate their problem definitions.

During training the parents discussed three factors that also explained their poor problem definition skills. Firstly, their limited knowledge about the roles of the SLT and other ECI professionals such as occupational therapist; and the impact that this had during consultations. Typical responses included: *"I don't know what information is important to tell each one... so I tell the same thing to all of them,"*; and, *"...I don't properly know what each one does.... I just wait for them to ask questions."* Secondly, their beliefs and perceptions about their role during the consultation included: *"To be quiet and listen to the therapists.... They know what they doing,"*; *"They are very busy... have long queues of patients... We can't talk too much,"*; and *"In my culture the mother must check with the father or elders before talking to professionals."* Thirdly, their concerns about language and cultural differences between themselves and the SLTs. The parents indicated that while they spoke English, their competence was *"...Not good like the therapist,"* and that they did not have access to interpreters during consultations at the hospitals. Table 15 indicates that the majority of the parents were Black, first language isiZulu speakers (60% of the experimental and 57.89% of the control groups), while 88% of the resident SLTs at the selected public hospitals were Indian, English first language speakers. All of the parents said that they were anxious during the first consultation with the SLT and *"...Did not say everything about my problems..."* while some said *"... I felt she will not understand these things about my culture and the disability... I didn't talk about it but it worried me."* The three factors are comparable to those already identified as challenges for parents' problem definitions during ECCI (Section 2.3.2.2). Similar findings are evident in a recent South African case study that explored the reasons as to why inpatients' did not seek clarity on information given during medical consultations at a public hospital (Mabuza, Omole, Govender & Ndimande, 2014). The reasons related to inpatients' perceptions of their relationship with health care practitioners (e.g. practitioners were too busy or aloof; inpatients' unquestioning trust and poor self-esteem); Mabuza et al. (2014) recommended training for inpatients to communicate effectively with healthcare practitioners.

Therefore, the parents' poor problem definition skills at pre-training were similar to global trends in research on health literacy, and indicated a critical need for parent training. The explanations proposed for the findings in this study suggested specific issues that were important to promote effective problem definitions for ECCI. Firstly, training needed to include knowledge, attitudes and skills that facilitated the following: the parents' active role and self-efficacy during parent-professional consultations; the evaluation of traditional practices that guided the role of the mothers and fathers during consultations; a systematic approach to the parents' definition of their problems and needs; the roles of ECI professionals and the SLT; and positive orientations toward the causes and outcomes of established disabilities. The findings highlighted the important influence that the parents' problem orientations had on their problem definition skills in ECCI. Secondly, although there was a gradual increase in the number of Black SLTs in South Africa, the findings highlighted the critical need to train more Black SLTs to meet the needs of the majority of parents in the country (Moodley, Louw & Hugo, 2000; NPC, 2011; DSD, DWCPD & UNICEF, 2012; Kathard & Pillay, 2013; Moonsamy & Kathard, 2015). Concurrently, findings illustrated that although education and training institutions in South Africa have prioritised competencies that equip SLTs to practice in diverse socioeconomic, cultural and linguistic contexts (Department of Health & Health Professions Council of South Africa, 2012), the need for SLTs to receive ongoing support through continued professional development was evident. This was imperative, especially since the majority of the SLTs within the country were first-language English speakers, who did not share the language and culture of the majority Black population (Kathard & Pillay, 2013; Pillay & Kathard, 2015).

***Review of key findings at post-training:*** Training successfully shifted the parents' problem definition skills from poor at pre-training to moderately good at post-training, with respect to the two core dimensions of providing organised and relevant information (Table 25). The parents' descriptions of their problems and needs were somewhat organised (Dimension 1) because although they showed knowledge of the three components of problem definition, they were unable to consolidate information in each component and present it systematically from one component to the other to promote the SLT's full understanding of the problem (Appendix K). Findings also suggested that the parents were better skilled in providing information in all three components of the problem definition construct, unlike pre-training findings which implied

slightly better skills in defining needs compared to problems and the obstacles. An example of one parent's response at post-training was:

*My child is not talking. He makes sounds... but I can't understand. He looks at me when I talk. Sometimes I think he can understand... I'm not sure. I talk to him like when I bath or feed him. He listens. He can't walk too. He's 3 years old. He was born sick. The doctors said he's got cerebral palsy. I take him to hospital every month... I try when I have the money. I'm not working. It's very hard. I don't know what he wants when he cries... is he in pain... hungry? It's stressful for me. If he can just point when he's hungry, thirsty, it will help so much.*

The relevance of the parents' descriptions of their problems and needs (Dimension 2) increased from poor to moderately good, and enabled the SLT to obtain a somewhat good understanding of the problem. The increase was attributed to the parents providing more specific, concrete and comprehensive information (Table AK4) in relation to the ICF categories of body structure and functioning, activity and activity limitations, and participation restrictions, as well as personal and environmental factors (WHO, 2001). The information was specific to the child's communication disability and/or associated conditions. Descriptions and/or explanations were drawn to a fair extent from the family's daily life context, contained familiar words and terms, were illustrated with a fair number of examples, and were almost comprehensive (Table K2). The overall findings implied further that the SLT raters had a generally good understanding of the problem and needs, which facilitated relevant ECCI planning to a large extent (Table AK4). However, mean scores remained below four, which reflected that the parents did not achieve full competence in problem definition (Table 25). The findings therefore implied that ongoing support was required to strengthen the parents' knowledge and skills in areas that were still vulnerable in both dimensions. The credibility of the findings is reviewed in relation to previous research, the training programme, and the overall theoretical framework of problem orientation and definition proposed in Section 2.3 and Table 1.

***Review of positive findings in relation to previous research:*** Although direct comparisons with the studies listed in Table 3 were not possible due to differences in research aims, designs and interventions, the similarity in findings was noteworthy and highlighted that parents can be supported to organise information according to problems and needs (Frederikson & Bull, 1995; McCann & Weinman, 1996); and to provide detailed information thereof (Frederikson & Bull, 1995; Cegala et al., 2000). The findings in this study, however, extended

previous research results through the use of the three-step framework of problem definition proposed in Figure 3 (D’Zurilla, 1986; D’Zurilla & Nezu, 1999, 2010; Dunst et al., 1994a; Grunland et al., 2005; Dunst, 2004; Spagnola & Fiese, 2007; Bernheimer & Weisner, 2007; Fiese & Sameroff, 1999; Sluzki, 1992; WHO, 2001). The framework provided the parents with specific, concrete guidelines in two areas: how to organise information as problems and needs in order to facilitate the SLT’s understanding; and what information was “relevant” to include, in order to access effective and sustainable ECCI.

**Review of positive findings in relation to the training programme:** The review of the training programme in Section 5.3.1 reflected that issues pertaining to the aims, philosophy, content, structure and process, trainer, and environment played important roles in promoting positive outcomes in the parents’ problem definition skills as well. Similar to Table 26, Table 27 reviews how the training principles were hypothesised to have influenced statistically significant outcomes in the two dimensions of problem definition, namely, organisation of information and relevance of information (i.e., specificity, concreteness and comprehensiveness). The table focuses on training methods that were considered influential in achieving positive outcomes for the parents in this study, particularly at the motivation and initiation phases.

Table 27

*Influence of training principles on positive outcomes in parents’ problem definitions and implication for parent support in ECCI*

<b>Summary of training principles</b>				
<b>Family-centred, collaborative parent-professional partnership</b>				
<b>Training phase</b>	<b>Training process</b>	<b>Training methods</b>	<b>Influence in facilitating positive problem definition outcomes &amp; implication for parent support</b>	<b>Change facilitated in:</b>
<b>Strengthen motivation to change</b>	Social Emotional	Modeling Learner input Video 1 - Confident parent’s story of ECCI	- Highlighted need for the parent to be assertive, participate actively in ECCI. Reinforced important role as advocate for the child. Story included parenting and intervention challenges and how these were addressed. <i>Implication: Parent must see how active participation facilitated their access to help needed</i>	<b>Problem orientation</b>  Personal control - self efficacy

<i>Summary of training principles</i>				
<b>Family-centred, collaborative parent-professional partnership</b>				
<b>Training phase</b>	<b>Training process</b>	<b>Training methods</b>	<b>Influence in facilitating positive problem definition outcomes &amp; implication for parent support</b>	<b>Change facilitated in:</b>
<b>Initiate change</b>	Cognitive	Lecture (parent-professional collaborative problem solving – both experts) Trainer input	- Recognised that collaborative partnership was accepted practice in ECCI. Reassured the parents that active participation was expected, and valued - not disrespectful to professional - Trainer developed respectful, participatory relationship with the parents. Parents had a “voice and choice”. Reinforced a safe, non-judgemental, empowering training context	<b><i>Problem orientation</i></b>  Personal control - self efficacy - outcome expectation
	Social Emotional	Problem-solving group discussion to manage cultural perceptions of the mother’s role in problem definition	Mothers who successfully managed cultural restrictions that were placed on their role during consultations , shared experiences and strategies. <i>Implication: Clarify parent’s role during ECCI to facilitate information sharing. Include methods that address relevant cultural issues</i>	Problem attribution (initial & maintaining causes)  Problem appraisal
	Cognitive	Lectures (transactional regulation theory of causation)	- Initiated cognitive re-framing of blame and stability of disability so that elements in the problematic situation were identified for support in ECCI. <i>Implication: facilitate adoption of a hopeful perspective - precipitates information sharing</i>	Commitment of time and effort to learn
	Cognitive	Lecture Handout (problem definition framework and significance for successful intervention planning) Modeling - simulated videos demonstrating good and poor problem definition Critical evaluation of outcomes for effective & sustainable ECCI planning	Recognised importance of SLT’s understanding of the parents’ problems and needs for effective and sustainable ECCI planning. Understood how systematic provision of specific, concrete and comprehensive information facilitated SLT’s understanding. <i>Implication: Make the clinical decision-making process overt - motivates informed information sharing from parents</i>	<b><i>Problem Definition</i></b> Organising information into three components (i.e. what is problem and why; what is need and why; obstacles preventing attainment of need)
	Behavioural	Role play with peers, individual practice of problem definition skills, and constructive feedback	Knowledge, practice, and feedback facilitated learning and confidence <i>Implication: Constructive feedback facilitated self-evaluation skills - important for generalisation</i>	Providing relevant information (i.e. specific, concrete, & comprehensive)

<i>Summary of training principles</i> Family-centred, collaborative parent-professional partnership				
<b>Training phase</b>	<b>Training process</b>	<b>Training methods</b>	<b>Influence in facilitating positive problem definition outcomes &amp; implication for parent support</b>	<b>Change facilitated in:</b>
<b>Maintain change</b>	Cognitive Social Emotional Behavioural	Handout Practice Train resident SLT	Ownership for learning Monitor and strengthen the parents' problem definition skills after training	All above

***Training process and training methods:*** The review and implications listed in Table 27 suggest that three factors, specific to the training process and methods, were influential in facilitating positive outcomes in the parents' definitions of their problems and needs in ECCI. Similar to the influential factors in Section 5.2.1, the three factors had implications for the education and training of parents and SLTs. The *first influential factor* was the training sequence. Table 27 illustrates the critical influence that the initial training in problem orientation had in motivating and initiating positive changes in problem definition. It was hypothesised that the facilitation of the parents' positive problem orientations at the outset was instrumental in creating the most favourable *cognitive, emotional and social* climate for parents to interrogate negative cultural beliefs and knowledge about the causes of disability; and traditional beliefs and expectations regarding the role of mothers as information providers during ECCI (Section 2.3.2, Table 1). At a *behavioural* level, the ensuing positive changes in the parents' perceptions of self-efficacy and outcome expectations facilitated recognition of their personal control during ECCI (Bandura, 1998; 2001 in Figure Q1; Dunst et al., 2007). This in turn promoted the parents' active and meaningful engagement with problem definition training. The change process, however, was supported by the trainer's use of relational and participatory help-giving behaviours, which created a collaborative, safe and non-judgemental training environment (Dunst & Trivette, 2009). The parents recognised the centrality of their role in the parent-professional partnership, as envisioned in the study's main theoretical framework of integrated ECCI and family support (Dunst (2004). The review, again, highlighted that it is important that SLTs are skilled in creating a collaborative, family-centered partnership with the parents. In view of the influence of traditional cultural beliefs and practices on the attitudes and behaviours of South African parents in this study, it was critical that SLTs invested time and effort at the beginning of ECCI, to address the concerns that parents raised during POD training. These concerns hindered their

active participation in ECCI (e.g. fears about competence in speaking English, cross-cultural issues). Parents needed to know that SLTs, both internationally and nationally, were currently trained to work with families from diverse language, cultural and socio-economic backgrounds (American Speech-Language-Hearing Association, 2008; Department of Health, in press). Therefore, SLTs needed to inform parents about the current family-centered philosophy that underpinned ECCI, and the value placed on parents' active participation during problem definition (Appendix Q). However, the findings of research reviewed in Section 2.3.2.2 and the South African study by Mabuza et al. (2014) implied that greater efforts were required to strengthen undergraduate and graduate training, in order to address the parents' concerns (e.g. aloof attitude of professionals at public hospitals).

As the motivational component of social problem-solving (D'Zurilla & Nezu, 1999, 2010), problem orientation training facilitated parents' confidence as change agents, advocates and decision makers during ECCI. The review of parent communication intervention studies in Table 3 reflected that the participants' orientation to problems was not routinely assessed during intervention (Section 2.3.2). Although McCann & Weinman (1996) incorporated measures of participants' self-efficacy and locus of control before and after training, these problem orientations were not targeted directly during intervention. The non-significant changes in these orientations at post-training highlighted that the provision of patient communication training only did not influence the participants' problem orientations. The evolving literature on problem-solving and positive functioning in different contexts (including health) recommended the inclusion of and the sequencing of problem orientation training prior to training in problem-solving (D'Zurilla & Nezu, 2010). The findings in this study therefore supported these recommendations.

The *second influential factor* was the parents' understanding of the importance of each component of the problem definition framework proposed in Figure 3. Central to this understanding was the SLT's demonstration of how the information was used to develop intervention plans that addressed the parents' problems and needs (as outlined in the training handout in Appendix S). Many parents indicated that they had, "*Never really thought about how therapy programmes were planned,*" and that the information, "*Makes me see how important it is to talk about my problems... and what help I need.*" The finding implied that the parents' informed engagement during problem definition facilitated their provision of specific, concrete

and comprehensive information. From the perspective of parent empowerment, this study emphasised the need for parents to be “informed information providers”, and consequently contributed to our understanding of effective parent-professional partnerships in ECCI.

The third influential *factor* was the selection and alignment of culturally and linguistically relevant training methods with the sequence of the training process for problem definition - similar to the discussion for problem orientation training in Section 5.2.1. As noted, problem orientation training was crucial in strengthening the parents’ motivation to learn the problem definition skills proposed in this study. The video of a confident South African mother targeted social and emotional processes that promoted changes in the parents’ self efficacy (Figure Q1). The mother shared her experiences and challenges of parenting, and intervention for her child with severe disability. It enabled the mothers in the experimental group to identify with the mother’s story and her journey to becoming a confident mother who asked for the help that she needed from professionals. Lectures on the current philosophy of collaborative parent-professional partnerships, and transactional regulation theory of causation facilitated a hopeful perspective that empowered mothers to consider the benefits of active participation in ECCI, for the child and family. Learner input and problem solving discussions with the mothers in the group were resourceful methods to destabilise the negative cultural beliefs which restricted mothers as information providers. Similar to the study by Keller et al. (2014), the mothers emphasised that the support of other senior members in the family was crucial. Lectures and the POD training handout initiated changes at the cognitive level, and enabled the parents to learn about the two dimensions that underpinned good problem definitions (i.e., relevant information presented in an organised format - Figure 3). The two videos allowed parents to observe poor and good problem definition skills respectively (Appendix T). Trainer-guided evaluation of the videos helped the parents to focus on specific aspects of the two dimensions of problem definition, and to consider the implications for intervention planning. The parents used the training handout to evaluate the parents’ communication skills. At the behavioural level, role-play, individual practice (given as homework and implemented on Day 4), and the trainer’s and participants’ constructive feedback on individual presentations enabled the parents to develop their problem definition and self-evaluation skills. Their self evaluation skills were important for maintaining the new problem definition skills learnt (Dunst & Trivette, 2009). Research on adult caregiver training in ECI is supportive of the training methods that were used in this study

(D’Zurilla & Nezu, 2010; Trivette, Dunst, Hamby & O’Herin, 2009). The findings therefore implied that SLTs needed to be knowledgeable and skilled in education and training theories and practice in order to obtain similar outcomes in parents’ problem definition skills.

*Extent of positive training outcomes in the parents’ problem definition skills:* Despite the training received, the parents’ did not achieve full competence in problem definition at post-training. Instead, they attained “moderately good” problem definitions because mean scores were below four (Appendix M). Three factors may have contributed to this outcome, commencing with the shorter duration of training in problem definition (4.5 hours) compared to problem orientation (8 hours) in the total 16 hours of training outlined in Appendix U. The greater commitment of time to problem orientation training, however, was justified in view of the influence that the dimensions of personal control (self-efficacy and outcome expectation), problem appraisal and problem attribution had in facilitating positive outcomes in the parents’ problem definition skills (Table 27). The findings demonstrated the need for individual practice to be allocated more time during problem definition training in future support programmes. Secondly, due to the time constraints imposed in a 16 hour training programme, not all of the parents had the opportunity to participate in the individual practice of their problem definition skills on Day 4 (Session 2), and to receive individualised feedback from the trainer and group members. While both training methods were crucial for skills development, literature indicated that it was consistent application over a period of time that was important to attain complete competence (Dunst & Trivette, 2009; D’Zurilla & Nezu, 2010; Sawyer, 2006). The post-training measurements were done one week after training, and may therefore not have provided sufficient time for the parents to practice and improve their problem definition skills. The need for parents to receive professional support during this time was also evident, to enhance the positive effects that were derived from training. Thirdly, during post-training interviews the parents communicated their problems and needs to the trainer for the second time. Although they were told to approach the interview as though they were meeting the trainer for the first time, their familiarity with the trainer and the “role-play” that was required may have compromised their performance in the post-training interview. For example, some of the parents omitted information that they had given in the pre-training interviews (e.g. nature of the child’s established disability). The literature reviewed (e.g. Frederikson & Bull, 1995; McCann &

Weinman, 1996), and later studies (D’Zurilla & Nezu, 2010) highlighted the need for parents to demonstrate their communication skills in natural contexts, in order to obtain valid assessments of their communication. Therefore, parents were likely to achieve maximum competence in their problem definition skills with continued support in the specific areas mentioned.

*Review of positive findings in relation to the theoretical framework of problem definition proposed in this study:* Statistically significant findings in the two dimensions of problem definition (i.e., organisation and relevance of information) suggested that the theoretical framework of problem definition was relevant for training parents to communicate their problems and needs effectively during ECCI. The reliability of the problem definition rating scale (Appendix K) was also confirmed by inter-rater and intra-rater agreement analyses in Appendix AH. The theoretical framework of problem definition guided the development of the analysis process (Appendix M). In the absence of empirical data to indicate the precise contribution of each dimension towards attaining effective problem definition, both dimensions were equally weighted based on subjective analysis of the literature (Table 8; D’Zurilla & Nezu, 1999, 2010). It was therefore important that the assumption of equal weighting of the two dimensions of problem definition received empirical validation.

The significant improvement in the parents’ descriptions of their problems and needs implied that the SLTs obtained a fairly good understanding of problems and needs described during the rating process. This understanding facilitated effective ECCI planning to a large extent (in comparison to a limited extent, at pre-training) (Table AK4). Although the parents did not demonstrate complete competence in communicating their problems and needs at post-training, the reasons discussed did not include the theoretical basis of training. The increase in the SLTs’ understanding of the parents’ problems and needs from pre-training to post-training was very encouraging (Appendix AK). The finding implied that SLTs could use the framework to systematically evaluate parents’ descriptions of their problems and needs during consultations, and to identify and collect missing information so that all elements that were critical for successful intervention planning were included during the collaborative problem-solving process (Section 2.3.2.1). The framework was therefore used to develop a guideline that SLTs could follow during the case history interview (Appendix AL). The guideline ensures that SLTs collected relevant information about the parents’ problems and needs to facilitate successful

intervention planning in ECCI. It provided SLTs with an important tool to promote parents' satisfaction with ECCI, thereby addressing the study's main research problem, namely, parents' dissatisfaction with interventions that did not meet their needs (Section 1.2).

***Effect of problem orientation training in facilitating positive findings in problem definition:*** The findings suggested that problem orientation training played a crucial role in promoting positive outcomes for the parents' problem definitions. This finding implied that parents' communication of their problems and needs during ECCI was influenced by both their orientations to problems and their problem definition skills. It was therefore critical that SLTs were knowledgeable and skilled to identify problem orientation issues that maybe embedded in the parents' definition of problems and needs that they encountered in parenting children with communication and established disabilities (e.g. attributions of initial and maintaining causes of established disability; outcome expectations). The nature of these issues is discussed in the literature reviewed in Section 2.3.2. Early identification and appropriate management of negative problem orientations were important to facilitate parents' communication of their problems and needs, and thereby effective and sustainable ECCI.

***Positive effects of training greater in problem definition compared to problem orientation:*** The finding was noteworthy and implied that the parents' problem definition skills were currently poorer than their problem orientations skills. It highlighted that parents' competence in communicating their problems and needs received minimal recognition as a contributory factor to achieve positive outcomes in ECCI. Consequently, very little attention was given to enabling and empowering parents to become competent information providers and help-seekers during ECCI. The finding supported the argument proposed in Section 1.2, which motivated for parents to be supported to seek help effectively from professionals in ECCI. The positive outcomes in the parents' problem definition skills underscored the effect that an evidence-based four-day, 16 hour POD training programme could have in enabling parents to become effective help-seekers in ECCI. The parents' positive evaluations of the training provided additional support (Table AH8).

The study's positive findings supported the need to expand our clinical and research focus from professionals' help-giving to parents' help-seeking. It is a viable step to improve the delivery of effective, sustainable and versatile ECCI to families of children with moderate to

severe communication disabilities, secondary to established disabilities. In light of the growing field of research on parents' communication with health care providers (especially in the medical field), the findings also clearly highlighted the critical role that SLTs can play in this regard.

### **5.3 Summary**

This chapter interpreted the statistically significant findings of the research and discussed the research and clinical significance in relation to the research problem and relevant literature. Factors that accounted for the positive effects of the training programme were considered. The use of a problem-solving approach which focused on parents' orientation to, and definition of problems experienced in parenting children with moderate to severe communication disabilities emerged as a viable strategy to support parents' in accessing relevant ECCI.

## CHAPTER 6

### CONCLUSION, EVALUATION AND RECOMMENDATIONS

#### 6.1 Introduction

The aim of the study was to determine the effect of POD training on parents' orientation to and definition of problems experienced in parenting young children (0-6 years) with moderate to severe communication disabilities. This chapter provides an overview of the research process and conclusion. A critical evaluation of the strengths and limitations of the study follows, concluding in recommendations for further research.

#### 6.2 Overview of research and conclusion

Parents' of young children with moderate to severe communication disabilities secondary to established disabilities encountered various parenting challenges, however, many parents were not skilled to access intervention that met their needs (Dunst et al., 1988, 1994; Neely-Barnes & Dia, 2008; Saloojee et al., 2007). This was evident nationally and internationally in parents' dissatisfaction and poor participation in ECI (Harry, 1992; Björck-Åkesson & Granlund, 1995; DSD, DWCPD & UNICEF, 2012). The problem was addressed in the ECI literature, by primarily increasing professionals' help-giving capacity to meet parents' needs (Dunst et al., 1994; Rossetti, 2001; Dunst et al., 2007). This study took the road less travelled in the field of ECI by strengthening parents' *help-seeking capacity*, so that they were empowered to access the help that they needed.

A parent training programme was developed and tested to facilitate parents' effective help-seeking, specifically in ECCI. The study innovatively borrowed from the field of psychology to propose a problem-solving approach to help-seeking, focusing specifically on parents' orientation to and definition of problems experienced in parenting young children (0-6 years) with moderate to severe communication disabilities, secondary to established disabilities. Parents' orientation to and definition of problems are the first two stages of social problem-solving theory, and are deemed critical in facilitating positive outcomes. A quasi-experimental non-equivalent groups pre-test-post-test control group design was used to plan, implement and analyse training outcomes in 34 parents (i.e., two functionally equivalent groups comprising

15 in the experimental group and 19 in the control group), during 16 hours of training that was done over four days.

Overall results revealed positive effects of training on the parents' problem orientation and definition, with greater effects in problem definition. Firstly, while the parents' problem orientations were largely in the positive range at pre-training due to parents access to ECCI, training outcomes were significant in supporting the parents in three dimensions: to appraise their children's communication and established disabilities as a challenge (problem appraisal), to view the cause of the established disability more positively (problem attribution), and to feel more confident to access support from family and friends (personal control - self-efficacy). These three dimensions highlighted vulnerabilities in the parents' coping, which were not supported in current ECCI programmes. These vulnerable areas hindered their capacity to function positively as help-seekers. The findings suggested that the parents' attributions about the initial, and specifically the maintaining causes of disability, were critical in motivating them to initiate and sustain help-seeking in ECCI.

Secondly, the parents demonstrated poor problem definition skills at pre-training, which implied that they were not competent in defining their children's problems and needs effectively in order to access the help that they needed, despite attending ECCI. Positive effects of training were evident in the two dimensions (i.e. organization and relevance of information) of problem definition, at post-training. The findings indicated that the parents' capacity to select relevant information about their problems and needs, and to communicate it in an organised manner had improved significantly so that the SLTs could provide ECCI that would meet the parents' needs. The findings also suggested that the parents' problem orientations were important in facilitating or hindering their problem definitions. The positive training outcomes were encouraging, particularly for culturally and linguistically diverse South African parents from poor backgrounds. It demonstrated that parent competence in problem definition could be strengthened to contribute to the identification of problems and ECCI needs of their children. This would lead to effective and sustainable ECCI. The study's POD training programme therefore identified a specific set of training methods that appeared relevant in achieving positive outcomes for South African parents from diverse socioeconomic and cultural backgrounds.

To answer the main research question, it is concluded that POD training had a positive effect on the parents' orientation to and definition of problems experienced in parenting young children with moderate to severe communication disabilities, with greater positive effects noted in their definition of problems compared to their orientation to problems. The clinical implications are hopeful. Problem orientation and definition training appeared to be a viable approach to support parent competence in initiating and accessing the help that they needed from ECCI. It was therefore a feasible strategy to address the clinical problem of parents' dissatisfaction with intervention received, and their subsequent poor attendance and participation in ECCI.

### **6.3 Critical Evaluation of the study**

It was important for the researcher to consider the scientific impact of the study to contribute new knowledge that could prove critical in moving research and clinical practice forward in new directions. In this context, some of the important strengths and limitations of the study are considered.

The most important strengths of the study include:

- The selection of evidence-based theoretical frameworks as the basis for conceptualising, developing and implementing parent support in help-seeking. The study's unique contribution to ECCI specifically (and ECI broadly) is the conceptualisation of parents' help-seeking from the theoretical viewpoint of social problem-solving, specifically the stages of problem orientation and problem definition. This focus is in line with current research and clinical trends in psychology and rehabilitation toward optimizing the positive functioning of individuals (D'Zurilla & Nezu, 1999, 2010; Hill, 2011). The inclusion of both stages strengthened the validity of the findings, although the specific influence of one on the other was not the focus of this study. Parent support in help-seeking was conceptualised and operationalised within the capacity-building paradigm, and utilised the principles of promotion, empowerment, strengths-based, resource-based and family-centred intervention (Dunst, 2004; Dunst et al., 1988, 1994; Neely-Barnes & Dia, 2008). The focus is aligned with the key tenets of South Africa's National

Development Plan (NPC, 2011), which advocates for people to be “active champions of their own development” (p.1).

- The central elements of the theoretical framework of parents’ orientation to and definition of problems that was developed for this study (Figure 2), provided a systematic approach to strengthen parents’ capacity to seek help in ECCI. The core framework contains generic principles that have the potential for wider application in the discipline of Speech-Language Therapy, as well as other disciplines in the fields of health-care, and education and training. Firstly, the framework of problem orientation provides SLTs with a systematic process to evaluate parents’ coping and positive functioning at the onset of ECCI. The outcomes could be used to individualise support for parents, and to refer for further professional support if required (e.g. psychologist). Similarly, SLTs could use the framework of problem definition to ensure that the two critical issues that underpin effective problem definitions are ascertained from parents to facilitate successful outcomes during the collaborative problem process (i.e. relevant information that is organised to promote problem resolution). The framework of problem definition is particularly novel in its simple yet robust structure, and applicability for collaborative problem solving with SLTs and parents from diverse linguistic, educational and cultural contexts. Secondly, both frameworks can be adapted by other health-care and education professionals to train and support individuals’ help-seeking capacities in ways that are specific to the discipline (e.g. occupational therapy).
- The pre-experimental phase of the study included a comprehensive, evidence-based operationalisation process to develop the data collection and analysis instruments, and the POD training programme. Expert reviews and pilot studies were used to establish validity and reliability of these instruments. Key principles of a systems approach to change were followed to address issues of social validity and sustainability of the training programme. Needs analyses were conducted through focus group discussions with the key stakeholders in the study, to establish concerns and needs regarding help-seeking and help-giving in ECCI. The analyses ensured that training met the needs of both parents of children with moderate to severe communication

disabilities, secondary to established disabilities; and SLTs working at public hospitals. Expert reviews and the pilot study further enhanced the social validity of the training programme. The development of social networks among the parents during training, and the plan to train resident SLTs after the study, were two aspects that ensured the maintenance of positive training outcomes.

- Positive training outcomes in parents' problem orientations and problem definition skills were obtained through research that was implemented in real-world settings and challenges (Bagnato et al., 2011). The findings provided practice-based evidence for a specific set of training components that were applicable for South African parents from diverse linguistic and cultural backgrounds, who lived largely in lower socioeconomic conditions. The training handout in particular, was an important outcome of the study that could be used by SLTs to promote parents' competence in seeking help during ECCI.
- Positive training outcomes overall in problem orientation and problem definition, and especially problem definition, also provided strong evidence to support the unique expertise that SLTs' bring to the training process. The findings demonstrate the important contributions that SLTs can make in the fields of health literacy and mental health.
- Training in problem orientation suggested two important outcomes. Firstly, that problem attribution, problem appraisal and personal control were core dimensions that facilitated South African parents' positive orientations toward the children's established and communication disabilities. Secondly, that the parents' problem attribution, specifically their perception of the maintaining cause of established disabilities, was critical in motivating the parents to change their negative orientations. The parents' knowledge of the transactional context of causation emerged as the central activator of their positive orientations.
- High interview and training integrity ratings, as well as inter-rater reliability ratings for coding of interviews provided support for the reliability of the study outcomes. The ecological validity of the ratings were enhanced through the use of SLTs, who possessed the typical level of knowledge and experience

that would be encountered in ECCI (Schlosser, 2003). The findings also implied that SLTs could be trained to implement the rating tools.

The following can be viewed as limitations of the study:

- The use of non-probability convenience sampling and the small sample size limited the generalisability of findings to South African parents in this study. Given the sampling method though, the experimental and control groups were functionally equivalent. The small scale of the study, however, was adequate as a first step in evaluating the suitability of the social problem-solving framework for supporting parents' help-seeking in ECCI.
- Inter-rater reliability differences in the SLT ratings of problem definition maybe considered a limitation. However, the finding drew attention to important variations in the way experienced and inexperienced SLTs may process information that parents provided during problem definition. This finding was very relevant because it demonstrated two issues: (i) the challenges of parent-professional communication in diverse socio-economic, linguistic and cultural intervention contexts (Kalbfleisch, 2009; Mabuza et al., 2014), and (ii) the implications for effective intervention planning based on professionals' understanding of parents' problems and needs (Tourmen, 2009; Burger et al., 2010).
- As in most research in ECI, the sample included predominantly mothers, with only one father. Previous research (Neely-Barnes & Dia, 2008; Lundahl et al., 2009) and the findings in this study (Section 5.2.2) highlighted that fathers played a critical role in the decision-making to access ECCI, especially in families from culturally diverse and traditional backgrounds. However, the families' perception of care-giving as a maternal task, may be a barrier to obtaining greater father involvement in clinical and research programmes involving children's disabilities (Harry, 2002; McConkey, 1995; Kisanji, 1995; Saloojee et al., 2007). Although changes in perceptions were occurring, as evident in research on men's involvement in South African families affected by HIV/AIDS (Montgomery, Hosegood, Busza & Timæus, 2006), the pace was slow. There was therefore a critical need for SLTs to use wider sociocultural approaches to educate parents about the development of children

and their communication skills; as well as the factors that facilitated positive outcomes for children and families. In addition, the use of innovative recruitment strategies is required to motivate fathers to participate in ECCI and research. Family involvement in ECCI (both mothers and fathers) remains important in order to facilitate sustainable intervention outcomes (Alant, 2005a; Neely-Barnes & Dia, 2008; Samuels et al., 2012).

- One of the participant selection criteria was to include families who attended ECCI for 0-12 months, in order to obtain a suitable sample size for statistical purposes. Initial efforts to recruit parents who attended ECCI for 0-3 months were unsuccessful because the parents were not keen to participate at this early stage, post-diagnosis. However, the parents' exposure to ECCI may have contributed to the positive findings in their problem orientations at pre-training, and masked parents' true orientations at the time of diagnosis.
- The problem orientation construct, as proposed in the social problem solving theory (D'Zurilla, 1986; D'Zurilla & Nezu, 1999, 2010), was the main framework that was used to develop the Problem Orientation Questionnaire (Section 3. 4.1.1). Since the questionnaire was developed as a preliminary measure in this study, the basic measures of face and content validity and reliability were considered adequate for this purpose (McMillan & Schumacher, 2010; Leedy & Ormrod, 2013). More rigorous methods such as construct validity and internal consistency (to assess reliability) were therefore not included. Although the questionnaire had an inconsistent number of items in each dimension, the inconsistency was largely due to the theoretical basis of the dimensions. For example, in this study there was no need to include more than one item to evaluate the dimension of problem appraisal. The similarity in findings between this study and the studies reviewed in Section 2.3.1 was noteworthy. It was important that validity and reliability testing was ongoing because the questionnaire had great potential for further enhancement. For example, construct validity and internal consistency.
- In the absence of empirical validation of the multidimensional status of the problem orientation and problem definition constructs, and the nature thereof (i.e., latent versus composite constructs), the constructs were measured through the analysis of the individual items in each dimension. Descriptive

analysis was then used to conclude on each dimension, and the overall construct (Appendix 1 and Appendix M). While descriptive analysis provided a general finding for the constructs of problem orientation and problem definition, further clarity about the empirical basis of the constructs as latent or composite was essential in order to refine and thereby increase the validity of the measurement process (Wong & Law, 2008). Empirical validation of the multidimensional status of the constructs was also important, in light of the implications for identifying core dimensions for POD training.

- The one-day training programme that was provided to the control group parents after the main study was very brief in comparison to the four-day training that the experimental group received. Group discussions and practice times were limited. However, the short duration was specifically planned to address the time-constraints that these parents identified during the pre-training interviews. The parents chose to attend the one-day training. The trainer ensured, though, that the key training aims were included, that parents had access to the small group of experimental group parents who participated in the one-day training, and that parents received all the training resources that were given to the experimental group (e.g. handouts, gratitude journals).

#### **6.4 Recommendations for further research**

Further research in parent support was strongly advocated to clarify pivotal questions of intervention effectiveness, namely; what support, for which parent, at which time, and in what setting (Post et al., 2002; Schlosser, 2003; Neely-Barnes & Dia, 2008). Hence, the following recommendations are proposed in relation to this study:

- Establish conceptual and theoretical precision regarding the status of problem orientation and problem definition as multidimensional constructs, and to subsequently clarify the underlying structure of each as factor or composite constructs. The specific contribution of each dimension and respective sub-dimensions is also important to ascertain, for each construct. This conceptual transparency will establish the level of contribution that each dimension and sub-dimension makes towards the outcome of the final problem orientation and problem definition constructs. Factor analysis and structural equation

modelling are relevant research methods for establishing conceptual clarity (Law & Wong, 1999; Wong & Law, 2008). Conceptual clarity will have further implications for refining and enhancing valid and reliable measurement of the constructs. The isolation of core dimensions and the direction of influence among the dimensions will increase effective understanding of the specific mechanisms that facilitated change. This would enhance the validity of intervention research. Parent activation studies using qualitative methods (e.g. parent interviews) were also important to identify processes that underpin change during training (Lipkin, 1996; Scorgie, Wilgosh & Sobsey, 2004). This would guide the selection and sequencing of core dimensions and training methods to promote positive outcomes (Alegría et al., 2008)—particularly for parents from diverse socio-economic and cultural contexts. Finally, to further enhance positive training outcomes, it was crucial to establish conceptual clarity about the nature of the partially independent relationship between the problem orientation and problem definition constructs (D’Zurilla & Nezu, 1999, 2010).

- Evaluate the sustainability of the training outcomes and thereby the long-term effectiveness of the training programme, through longitudinal follow-up studies of the same groups of parents in the experimental and control groups, using the same measuring tools. These evaluations should also document the underlying mechanisms that influence the sustainability of positive training outcomes for South African parents in general. In this way, advances can be made in enhancing the quality and cost of ECCI practice, specifically for culturally and linguistically diverse families living in poor socioeconomic conditions.
- Increase the credibility of training outcomes by following the principles of the randomised control experimental design strictly, using a larger sample and paying close attention to factors regarding participant selection. For example, equal distribution of mothers and fathers; and controlling parents’ exposure to ECCI. Innovative recruitment strategies need further investigation to recruit parents who are in the early stages of diagnosis, and a greater number of fathers. Relevant guidelines may be accessed from Stevens, Lord, Proctor, Nagy, and O’Riordan (2010) on researching sensitive topics with vulnerable

families (e.g. through the appointment of research assistants that families' could relate to); and Alant (2005b) on community development and the relevance of community associations in producing "a context within which care is manifested." (p. 161).

- Further rigorous testing of the Problem Orientation Questionnaire to establish construct validity and to identify the underlying construct being measured. Methods such as contrasted groups or the multi-trait, multi-method approach may be pursued. Reliability testing should measure the internal consistency of items, using statistical tests like the Crohnbach's alpha coefficient.
- Establish the specific effectiveness of the different training methods that were used to facilitate parents' positive orientations and effective definitions of problems, through dismantling research designs such as multiple baseline studies (Neely-Barnes & Dia, 2008; D'Zurilla & Nezu, 2010). The findings will guide trainers in selecting methods that were most beneficial to South African parents, and cost effective for under-resourced contexts.
- Ascertain the specific information processing skills that experienced and inexperienced SLTs used in order to understand parents' definitions of problems and needs during ECCI, particularly when parents provided limited information thereof. Research on clinical decision-making and the facilitation of critical thinking skills will be useful in this regard (e.g. Carter and Iacono, 2002; Tourman, 2009; Burger et al., 2010; & Chabeli, 2007). The findings will guide undergraduate training programmes to include specific teaching and learning activities that will enhance SLTs' critical thinking skills during clinical decision-making.

## 6.5 Summary

This concluding chapter commenced with an overview of the rationale for the study, summarised the main research findings and presented the final conclusion to the main research question. The study was critically evaluated with respect to its strengths and limitations, and relevant recommendations were made for further research. The study took a small step toward understanding parent participation in ECI and particularly in ECCI, by contributing new knowledge about the viability of parent support in problem orientation and definition. The findings are valuable to

professionals and families of children with disabilities, and broadly to the emerging fields of health literacy and mental health in Speech-Language Therapy. It is also clear, though, that further research is required to strengthen parents' help-seeking capacities.

Problem orientation and definition are life skills that have a universal appeal. The theoretical contribution of this study could be applied broadly to make every-day living more solution focussed. Although this study was developed for disempowered parents from a poor context, the central tenets are relevant in facilitating positive functioning in parents from any context.

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## Appendix A

### Sample of descriptive studies that exemplify research on parents' positive functioning in parenting children with disabilities

Authors & place	Study design & Participant profile	Findings on parents positive coping & functioning - <i>includes five dimensions of problem orientation</i>
<b>Scorgie, Wilgosh, McDonald (1996, 1999); Scorgie &amp; Sobsey (2000)</b>  <i>Canada</i>	Qualitative (i) Interviews with 15 parents of children (3-25 years) with varied range of disabilities from urban and rural areas (ii) 80 parent surveys	Effective life management changes were identified in three areas: (i) <b>Effective strategies:</b> positive reframing of thoughts and attitudes regarding circumstances; balancing personal roles and responsibilities; identifying and utilizing resources effectively to meet parent, child and family needs. (ii) <b>Effective personal attributes:</b> (a) <i>six characteristics:</i> flexibility, patience, persistence/determination, positive outlook, sense of humour & willingness to accept help; (b) <i>decision-making and problem-solving ability</i> in confronting problems and taking control through constructive decision-making; (c) <i>philosophy of life</i> in deriving personal strength from strong inner convictions (e.g. religion/spirituality) (iii) <b>Transformational outcomes</b> involving image-making, meaning-making and choice-making in the <i>personal</i> (acquired new roles and traits); <i>relational</i> (family, advocacy, friends, attitude to people in general) and <i>perspectival</i> domains (awareness of priorities and values).
<b>Larson (1998)</b>  <i>United States of America</i>	Qualitative Interviews with six Mexican mothers (27-42 years) of children with severe disabilities (5-11years)	Parents reframed the meaning of disability to <i>embrace the paradox</i> of managing opposing forces (e.g. loving the child but wanting to erase disability; dealing with incurability but maintaining hopefulness). <b>Three methods:</b> (i) Positive evaluation of self and life circumstances (e.g. see self as better of than others with bigger problems) (ii) After initial loss of control at diagnosis, gradually regain control by revising and reconstructing meaning of event, and devising ways to solve problems of living (iii) maintain optimism. Energizes maternal work and fosters positive beliefs about future possibilities. Hope seen as pre-requisite for coping and adaptation in promoting actions to achieve meaningful lives.
<b>Grant &amp; Whittell (2000)</b>  <i>United Kingdom</i>	Qualitative Interviews with 30 families caring for children and adults (0-≥50 years) with intellectual disabilities, from rural and semi-rural communities. Families were at different stages of life-course, to reflect different service transition points.	Frequently used strategies identified in three areas: 1. <b>Managing events/problem solving:</b> - relied on personal experience and expertise - had a regular routine/structure for coping - access to trusting confidante, talk things over - set priorities - selected from repertoire of coping strategies 2. <b>Managing meanings</b> - realize there's always someone worse off than you - person cared for is not to blame - Maintaining high locus of control – belief in self and ability to handle situation - recognize that things are better now than used to be - accept situation and get on with things as effective way of coping 3. <b>Managing/alleviating stress</b> - keep a little free time for self - Engage in passive leisure pursuits to take mind off things for a while  <b>Gender differences in coping:</b> <b>Women:</b> better use of problem solving coping ie instrumental coping (finding help)

Authors & place	Study design & Participant profile	Findings on parents positive coping & functioning - <i>includes five dimensions of problem orientation</i>
<b>Taanila, Syrjälä, Kokkonen &amp; Järvelin (2002)</b>  <i>Finland</i>	Qualitative Interviews with eight parents (32-48 years) of children (8-10 yrs) with physical and/or intellectual disabilities	<ul style="list-style-type: none"> <li>- display greater self belief, and keep emotions under close control</li> <li>- draw on personal and religious beliefs greater than men</li> <li>- derive meaning from experience better than men because of above</li> </ul> <p><b>Men:</b> showed less mastery in coping, less confident in caregiving, and found it harder to derive meaningfulness</p> <p><b>Coping and the lifespan</b></p> <p><b>Preschool aged children:</b> Parents place stronger emphasis on problem-solving methods</p> <p><b>Older carers:</b> more resigned to role, more acceptance of how things are</p> <p><b>Lone carers/single parents:</b> face greater demands if nobody to share with, greater emphasis on cognitive coping strategies</p> <hr/> <p>Parents from <i>high coping families</i> :</p> <ul style="list-style-type: none"> <li>- experienced shock at diagnosis, but both spouses <i>recovered and accepted the situation</i> quickly.</li> <li>- <i>well informed</i> about child's diagnosis and treatment, and <i>actively sought information</i> to cope with stress</li> <li>- adopted <i>optimistic attitude</i> towards child and family's life and future, believing that child would manage with adequate support systems, enabling ability to cope later in life.</li> <li>- <i>open communication</i> of feelings and affections</li> <li>- values changed to <i>prioritize the family</i>.</li> <li>- parents <i>maintained hobbies</i> and found new ones.</li> <li>- spouses <i>shared</i> care-giving and household chores.</li> <li>- maintained extensive and supportive <i>formal and informal social support network</i>.</li> </ul>
<b>Maul &amp; Singer (2009)</b>  <i>United States of America</i>	Qualitative Interviews with 10 participants (parents or grandparents 31-59 years), purposely selected because actively seek and obtain services for child, from advantaged backgrounds, and proficient in English. Children 3-8 years with varied disabilities.	<p>Specific accommodations made by families to adapt positively to parenting :</p> <ul style="list-style-type: none"> <li>- lost opportunities replaced by new ones (e.g. family outings)</li> <li>- close cooperation among family members (family as a team). Reassigned traditional roles between mother and father. Siblings and fathers assisted with care-giving.</li> <li>- modified pace of family life to accommodate child with disability</li> <li>- adjusted work schedules. Many mothers changed to part-time work or stopped altogether.</li> <li>- planned in advance.</li> <li>- accommodations were customized to suit individual family.</li> <li>- rejected stigmatization of children's disability and insisted on normalcy of family identify (i.e. not damaged).</li> <li>- decision-making entailed trial and error, until solution found. Conducted research ( readings, internet, attending conferences) to assist decision-making</li> <li>- good communication between parents</li> <li>- assistance from professionals in adapting family activities to accommodate child with disability.</li> </ul> <p>Detailed list of accommodations provided in Table 2 in the article (p. 163).</p>

## Appendix B

### Detailed summary of parent intervention studies to support parents' coping with children's disabilities.

Study	Aim	Methodology	Results
<b>Moxley-Haegert &amp; Serbin (1983)</b>	To compare the effectiveness of three treatment conditions on parents' motivation to participate in home programme	<p>Experimental and control group design involving 39 caregiver-child dyads equally and randomly distributed to one treatment and two control conditions: developmental education (DE - treatment); child management education (CME), and no education – both control. Children were matched for age (4-36 months) and severity (moderate and severe developmental delay), before even distribution of 13 to each group.</p> <p><i>Intervention:</i> Home programme and treatment supplies were provided before each treatment condition was introduced for 4 weeks. In DE parents were trained to observe and recognize developmental progress in child, given readings and 3 weekly visits to discuss readings and receive social reinforcement. In CME, controlled for effects of attention, study materials and social reinforcement. Parents given readings on child management (not specific to developmental delay or dealing with cognitive/motor development), received 3 weekly visits with discussion of readings and reinforcement. In no-education group, no visits and readings but received three telephone calls.</p> <p><i>Outcome measures:</i> Child - infant development. Parent - developmental knowledge, self report questionnaire on participation in home programme; leftover treatment supplies measured; questionnaire from occupational therapist treating child (at follow up). Measured at pre-, 1 week post intervention and 9-15 months follow-up.</p>	<p>Statistically significant differences between experimental (DE), and control groups (CME and no-education). Parents in DE group recognized and recorded greater number of gains made by children reflecting improved ability to discriminate and report on child's progress. Gains made by the DE group continued at post-intervention and follow-up assessments, but not seen with the two control groups. Recognition of small levels of developmental progress was seen to reinforce and motivate parents to increase participation in home programmes.</p> <p><i>Conclusion:</i> The “intrinsic reinforcement effect” was important to maintain parents' active participation.</p>
<b>Baker, Landen &amp; Kashima (1991)</b>	1. To establish whether participation in the child's intervention had a broader impact on	One group pre-post intervention design. Forty-nine families of children (2-11 yrs) with mental retardation due to unknown origin, Down Syndrome and autism were assessed pre-and post intervention, and one year later on training outcomes related to child and parent/family functioning.	1. Statistically significant effect on parents' teaching knowledge and skills, evident at one year follow-up. Small but statistically significant decreases in reports of depression, parent/family problems, family stress and dissatisfaction with family adaptation and cohesion.

Study	Aim	Methodology	Results
	<p>parents and families</p> <p>2. To establish whether parent and family characteristics predict successful outcomes</p>	<p><i>Intervention:</i> self help skill teaching and behaviour management over 11 sessions.</p> <p><i>Outcome measures:</i> (i) teaching knowledge and skills; (ii) parent reports on marital adjustment, depression, resources and stress, family adaptation and cohesion</p>	<p>2. <i>Significant predictors of drop-outs:</i> single parents, low marital adjustment, low income, low pre-training teaching skills, high family stress, low adaptation/ cohesion.</p> <p><i>Low follow-through families</i> entered training less positive about family, poorer marital adjustment, more dissatisfaction with family adaptation.</p> <p><i>Recommend:</i> inclusion of parent support for marital adjustment, family adaptation and decreasing stress – three important predictors of poor long-term outcome.</p>
<b>Bristol, Gallagher &amp; Holt (1993)</b>	<p>Assessed impact of a psycho-educational intervention on depressive symptoms of mothers of children with autism and severe communication disabilities</p>	<p>Experimental and control group design, non-random assignment 28 mothers – 14 per group</p> <p><i>Intervention:</i> specific to managing autism – therapist and parent work together to develop optimum individualized home program for child</p> <ul style="list-style-type: none"> <li>- Helping child to acquire better skills and reduce dysfunctional behaviour</li> <li>- Helping parent to adapt attitudes and structures in the home to accommodate special needs of child</li> <li>- Parents given one-on-one modeling, reinforcement, guided feedback</li> </ul> <p><b>Outcome measure:</b> maternal depression measured at 3 points: two weeks before and six and 18 months after intervention</p> <p><b>Analysis:</b> repeated measures analysis of variance</p>	<ul style="list-style-type: none"> <li>- Mothers in E group showed significant decreases in depressive symptoms over 18 month period, but not at 6 months.</li> <li>- Reflects gradual increase in maternal feelings of control and gradual improvement in depression. View depression as a <i>modifiable adjustment reaction to stress</i> of caring for child with chronic disability</li> <li>- <b>Non-random allocation of groups</b> - motivational or other factors may have influenced participation, so cannot be ruled out</li> <li>- <b>Without random allocation cannot say treatment caused decrease</b> in symptoms. Parents who chose to participate experienced marked decrease. No change seen in C group</li> </ul>
<b>Pelchat, Bisson, Ricard, Perreault &amp; Bouchard (1999)</b>	<p>To assess longitudinal effects of an early intervention programme on adaptation of parents of children with disability [Down Syndrome (DS) &amp; cleft lip and palate (CLP)]</p>	<p>2 group experimental &amp; control design, non-random allocation of 74 two-parent families. Data collected at 6 months, 12 months, 18 months.</p> <p><i>Intervention:</i> emphasized strength and family's adaptive capacity (i.e. autonomy, optimal actualization of internal and external resources; empowerment of family competencies important for adaptation and child care. Implemented by nurse. Six to eight meetings – two at birth, and four at parent's home.</p> <p><i>Measured:</i> three dimensions of parental adaptation: parental stress, emotional stress, spousal support.</p>	<p>Statistically significant effect on 10/16 adaptation measures.</p> <p>Interaction effects seen in 4/10 measures (role restriction, perception of challenge, control by self, instrumental support).</p> <p><i>Positive treatment effects:</i> parents felt less threatened; more confident to receive help from others; less emotional distress, anxiety and depression; perceived more emotional support from spouse. Mothers more inclined to see situation as a challenge. Parents felt greater confidence in using own resources to cope.</p>

Study	Aim	Methodology	Results
		<i>Analysis of treatment effect:</i> 3 levels - time of measurement; type of disability; parent's gender.	No difference in adaptation between the two groups of parents (DS or CLP) – attributed to receipt and timing of intervention.
<b>Morrison, Bromfield &amp; Cameron (2003)</b>	To describe a therapeutic model for supporting families of children with chronic illness or disability	Descriptive study outlining model for interventions, principles and methods. Types of <b>interventions</b> offered, e.g. counseling, psychological first aid, projects, peer groups, social events, community education - <b>Model principles</b> – family centered, non-illness specific, non-linear, preventive, flexible - <b>aim and methods.</b> Methods include: hope, empowerment, reconnection, coping & resilience, reframing,	Provides a relevant model for developing parent support intervention. Uses theory of traumatic stress, its impact on parent and the goal is to decrease stress. One focus is prevention. <i>Critical evaluation</i> – needs to focus on promotion and building strengths, not only avoiding stress.
<b>Barnett, Clements, Kaplan-Estrin and Fialka (2003)</b>	To describe a parent group intervention to promote adaptation to raising a child with special needs due to chronic medical conditions or disability	Descriptive study on the theoretical basis and practical implementation of a parent intervention programme. Theory is based on the need for parents' healthy adaptation, which facilitates attachment and bonding with the child, thus enabling sensitive and responsive parenting. Latter facilitates parent and child well-being. The programme is described, but not yet empirically evaluated. <i>Intervention:</i> 5 goals, includes help-seeking broadly; 8-sessions developed from the basis of social, emotional, cognitive and behavioral support, which is described in detail. Mechanisms of change, and parents' readiness to change are important issues raised.	Identifies a relevant four process theoretical framework that operationalises the mechanisms to develop parent support: social, emotional, cognitive and behavioural.
<b>Bolton (2004) South African study</b>	To describe a parent-child intervention to assist families in coping with young children at risk or diagnosed with communication difficulties	Description of a 16-week family-focused programme for young children with communication difficulties. Six workshops were provided on the following topics: communication, early literacy, play, fun and movement, healthy eating, attention-deficit hyperactivity disorder and children's self esteem. A graduation ceremony concluded the programme.	Child outcomes included increased communication, listening and concentration; greater interest in books and play. Caregiver outcomes included communicating effectively with the child, and providing more opportunities for communication; a <i>more positive relationship</i> with the child following better understanding of communication.
<b>Margalit &amp; Kleitman (2006)</b>	To examine factors that predict maternal stress pre-and-post intervention, and to identify	One group pre-and post intervention design. 70 mothers of children in the age range 0-3 years with developmental disabilities. <i>Intervention:</i> individual programmes tailored to baby's needs and level of functioning and parent support (peer support, meeting maternal needs,	- Maternal stress was significantly predicted by sense of coherence (SOC) scores (higher SOC predicted lower stress) at pre-intervention; and parents' coping strategies (individual perceptions) and family cohesion at post-intervention. Maternal

Study	Aim	Methodology	Results
	mothers who were resilient	facilitating parent- child transaction, etc.) <i>Outcome measures:</i> parenting stress, sense of coherence, family adaptation and cohesion, parent coping.	satisfaction with intervention was also significant. - Resilient mothers reported lower SOC and family adaptation and higher family cohesion scores post-intervention. Conclusion: Maternal satisfaction with intervention and belief in themselves (i.e. SOC and coping) predicted their experience of stress.
<b>Tonge, Brereton, Kiomall, Mackinnon, King &amp; Rinehart (2006).</b>	To assess the impact of a parent education and behaviour management (PEBM) intervention on the mental health and adjustment of parents of children with autism (2.5-5 years)	Three groups: randomized, group-comparison design involving PEBM (n=35) and parent education and counseling (PEC, n=33) intervention to control for nonspecific therapist effects, and a control group which received early childhood services (n=35). <i>Intervention:</i> 20 sessions (10 small group & 10 individual family sessions). Focused on education about autism and resources and cognitive-behavioral counseling on managing stress, grief and change. <i>Outcome measures:</i> general health (depression, anxiety etc) and stress assessed before, immediately after and 6 months after intervention.	Greater than 50% of the parents had serious mental health problems at pre-testing. The PEBM and PEC interventions were significant especially with parents who had pre-existing mental health problems. The benefits of PEBM and PEC interventions emerged over the long-term rather than short term, indicating cumulative benefit as parents applied skills learned. No statistical evidence of PEBM superiority over PEC.
<b>Herbst &amp; Maree (2006)</b>  <i>South African study</i>	To describe the development of an empowerment programme for parents in the NICU	Qualitative contextual study that describes two phases: (i) two focus groups (n=12; n=10) with parents of infants needing specialized care in the neonatal intensive care unit (NICU) to identify parent needs and suggestions for empowerment; (ii) a workshop with neonatal nurses (n=20) to develop guidelines for parent empowerment, using findings from phase one.	Parents identified the following needs and nurses developed supportive guidelines to empower parents: - information and orientation so they knew what to expect - informed decision-making to facilitate control of the situation - participation in basic care of the child - acknowledgement and support for intense emotions and coping, e.g. causal attributions/self blame/denial - sensitive communication with professionals that built trusting relationships; need for interpreter. - therapeutic NICU environment, competent staff, privacy, and preparation for discharge
<b>Barlow, Coren &amp; Steward-Brown (2009)</b>	To evaluate the effectiveness of group-based parenting programmes in improving maternal psychosocial	Randomised controlled trials involving 26 mothers of children from birth to adolescence with behaviour problems or disabilities (e.g. ADHD, intellectual disabilities, Down Syndrome etc). <i>Intervention:</i> group-based format, theoretical frameworks - behavioural, cognitive-behavioural, humanistic.	Statistically significant results favouring intervention group for outcome measures of depression, anxiety/stress, self-esteem, marital relationship – but not social support. Conclusion: Parenting programmes are effective in improving maternal psychosocial health in the short-term,

Study	Aim	Methodology	Results
	health (e.g. anxiety, depression, self-esteem)	<i>Outcome measures:</i> depression, anxiety/stress, self-esteem, marital relationship, social support.	but long-term effects are lacking and need further research.
<b>Black, McConkey, Roberts &amp; Ferguson (2010)</b>	To describe a person-centred support service for families caring for children with severe learning disabilities in rural and urban areas, and three year formative evaluation of the programme.	Descriptive and evaluation study. Support services geared <i>for parents and children /young people</i> with learning disabilities in association with established disabilities such as Down Syndrome, autism, sensory deficits. <i>Intervention principles:</i> strength and resource based, working in partnership with parents as key decision-makers / experts on child's needs, adopts a community development approach. <i>Outcome measures:</i> interviews and focus groups with parents (n=48); young people (n=19); volunteers (n=7); community workers (n=4) and referring social services (n=14).	Service was successfully implemented in one rural and two urban areas. Assisted parents to clarify individual support needs, and involved children in ordinary community activities with non-disabled children (e.g. outdoor games). Support was highly rated by parents, children, volunteers and staff. <i>Limitation:</i> participants volunteered which could have biased findings.

## Appendix C

### Problem-Solving Self-Monitoring (PSSM) Form (D’Zurilla, 1986, p 236)

*Instructions:* The purpose of this form is to record information about a significant problem which occurred in your life and how you attempted to solve it. A “problem” is defined as a situation in which you perceive a discrepancy between “what is” (present conditions) and “what should be” (conditions which are demanded or desired), but the means for reducing this discrepancy (a possible solution to the problem) are not immediately apparent or available to you. For each problem-solving situation, record the information requested below in sections A,B,C,D, and E. when describing this information, please be as *specific* and *concrete* as possible. If there is not enough room in the space provided to complete your description, you may write on the back of the page, but be sure to identify the section that you are continuing.

#### A. *Problem information* (PO & PDF)

In the space below, describe all the relevant facts about the problematic situation. Your information should provide answers to the following questions:

1. Who was involved?
2. What happened (or did not happen) that was unacceptable?
3. Where and when did it happen?
4. Why did it happen? (if reasons or causes are unknown)
5. Why was this problem important? (what was at stake? Was there a threat? Was there a challenge?)
6. What was your problem-solving goal? (what specific outcome did you desire?)

Please answer the following questions about the problem by circling the answer which best describes your view of the situation.

a. The *main* cause of the problem was:

1. An obstacle or deficiency in the environment (including the behavior of other people).
2. An obstacle or deficiency in myself
3. A combination of an obstacle or deficiency in the environment *and* in myself.

b. How important was the problem for your *overall well-being* (physical, psychological, social or economic)?

1. Slightly important
2. Moderately important
3. Extremely important

c. To what extent did you view the problem as a *threat* to your well-being (potential for harm or loss)?

1. Not at all threatening
2. Slightly threatening
3. Moderately threatening
4. Extremely threatening

d. To what extent did you view the problem as a *challenge* (opportunity for personal growth or mastery)

1. Not at all challenging
2. Slightly challenging
3. Moderately challenging
4. Extremely challenging

e. When you first recognised the problem, how likely did you think it was that the problem was solvable (that the factors causing the problem could be changed or controlled)

1. Very unlikely
2. Somewhat unlikely
3. Somewhat likely
4. Very likely

f. When you first recognised the problem, how confident did you feel in your ability to solve the problem through your own efforts?

1. Not at all confident
2. Slightly confident
3. Moderately confident
4. Extremely confident

g. When you first recognised the problem, how much time and effort were you willing to commit to the task of solving the problem on your own?

1. No time and effort at all
2. Some time and effort
3. Much time and effort
4. Very much time and effort

h. Compared to the time that you expected to spend on the problem, how much time did you actually spend on it?

1. Much more time than I expected
2. About as much time as I expected/ no more and no less
3. Somewhat less time than I expected
4. Much less time than I expected

**Note:**

**PO = Problem orientation**

**PD = Problem definition and formulation**

## Appendix D

### Detailed results of focus group discussion with speech-language therapists

CATEGORY	DESCRIPTION
Participants	Six participants were willing and met with the researcher at a local hospital that was suitable to all. A research assistant (community service speech-language therapist) was present to assist with audio-recording. The participants were familiar with each other, which contributed to an informal and non-threatening conversational context.
Aims	<p>To explore the perceptions of speech-language therapists about parents' orientation to and definition of problems experienced in parenting young children with moderate to severe communication disabilities (secondary to established disabilities), and to ascertain the need for parent support. The following questions were used to stimulate discussion, namely:</p> <p>i) Tell me about your experiences with parents when they first come to see you about their children's problems. Are you able to determine their attitude towards their child's problem (i.e. positive/negative)? <i>Prompt discussion with...</i> What does the parent say or do that helps you determine their attitude?</p> <p>ii) Do you think that the parent's attitude affects the child's progress in intervention? If so, how?</p> <p>iii) Do you find that parents generally give you enough information about their problem/s, to help you with intervention planning? [yes/no]</p> <p>iv) What are things that parents say or do when telling you about the problem/s, which makes it difficult for you to understand what the problem is? Hv) What are things that parents say or do when telling you about the problem/s that helps you to understand their problems better?</p> <p>vi) Is there a need for parents to be trained in: (1) how to define their problems so that they access the help they need, and (2) how to approach the challenge of raising a child with a disability? [yes/no]</p> <p>vii) If the answer is yes, do you think that speech-language therapists should be involved in providing this training?</p>
Method	<p>The researcher facilitated a semi-structured discussion of the questions, and utilized guidelines for focus group discussions by McMillan &amp; Schumacher (2010); Babbie and Mouton (2001); &amp; Hill et al. (1997). A research assistant was present to help with the audio-recording, and to ensure credibility of the data collected (Hill et al., 1997). At the outset, participants were informed about the purpose of the discussion, filled in informed consent forms and biographical information sheet (Appendix E), assured that they would remain anonymous, and that group (not individual) responses would be analyzed, thus ensuring confidentiality of individual responses. They were also informed that the discussion would be audio-recorded and transcribed, and that they would have access to the transcribed material to check its accuracy if they needed to. In addition, the facilitator gave a short summary of the discussions at the end of each question and participants were requested to indicate if it captured the essence of what they said or if any important issue was missing (Bornman et al., 2004). These "member checks" ensured trustworthiness of the data (McMillan &amp; Schumacher, 2010). The facilitator conveyed a non-judgemental approach indicating that she wanted to understand rather than judge participant's responses. Participants were encouraged to participate actively and freely when sharing their experiences (Bornman et al., 2004; Cresswell, 2014). The duration of the focus group was 1 hour.</p> <p>Directly after the focus group, the researcher and assistant had a debriefing session where each shared their interpretations of the discussions. The latter contributed to further enhance the trustworthiness of the data (Bornman et al., 2004; Hill et al., 1997). The researcher transcribed the discussion verbatim, and the assistant checked the transcript against the audio-recording to ensure that the transcribing was done accurately. Names and any information that could identify the participants were deleted</p>

CATEGORY	DESCRIPTION
Analysis	<p>to ensure the participants' anonymity.</p> <p>The researcher and assistant independently identified and summarized the key issues raised by the group, for each question. Thereafter, both met and discussed their summaries in order to guarantee consensus for each question. The latter ensured credibility of the analytic process and the data (Hill et al., 1997; Bornman et al., 2004).</p>
Results	<p>A summary of the key issues that emerged from the focus group included:</p> <p><i>Question (i):</i> Therapists were generally able to gauge parents' attitudes towards their child's disability. Parent behaviours highlighted included: acceptance/denial of problem; motivated/not motivated to learn to help the child; feeling helpless; self-blaming. However, therapists felt that they were not able to verify their perceptions with parents, as they did not have an appropriate method of evaluation. All felt that therapists should have a quick, systematic method of evaluating parent's attitude, and this information should be used in parent education and counseling initiatives. Currently, none of the therapists use any measure for evaluating parent's orientation/attitude.</p> <p><i>Question (ii):</i> All agreed that the parents' attitude toward the child's communication disability had either a positive or negative impact on the intervention process and outcomes.</p> <p><i>Question (iii):</i> The majority felt that parents gave broad concerns and needed to be questioned to get to the specific problem.</p> <p><i>Question (iv):</i> The following were found to <i>hinder</i> therapists' understanding: parents are not sure/don't know important developmental milestones; don't present all the information that they know because they don't want the problem to appear severe; present information in a haphazard manner, moving from one area to another without completing information; speak a language that therapist does not understand and there isn't an interpreter; do not give examples of the problematic behaviour as it happens in their daily context; parent is unable to communicate clearly or communicates very little, every piece of information has to be "pulled out"; parent appears passive or intimidated in the presence of professionals, which could be due to parents' limited education or cultural differences; parent feels that the child's communication is not a problem (when it is, as compared to peers of the same age from the same socio-cultural community).</p> <p><i>Question (v):</i> The following were found to <i>facilitate</i> therapists' understanding: parent provides many examples of the problem in different contexts (home, pre-school etc); the problem is described in a very coherent manner, starting from when it began to the present condition; parent has copies of previous assessments; parent is able to provide significant developmental, medical and other case history information; parent is comfortable talking to professionals.</p> <p><i>Question (vi):</i> All said "yes". Therapists felt that they needed a systematic method of evaluating the parent's approach to their child's disability, and the parent's skill in defining problems. With such a tool, they would be able to clearly identify which areas parents required support in.</p> <p><i>Question (vii):</i> All felt that all health care professionals should be skilled in supporting parents to use positive help-seeking behaviours when accessing intervention, especially in view of limited health care professionals in many hospital in South Africa. Speech-language therapists were considered to be particularly important in view of their expertise in communication. They also felt that interdisciplinary initiatives that included psychologists would be very beneficial in a hospital context.</p>
Implications	<p>All speech-language therapists supported the need for professionals to assist parents to function effectively as help-seekers. They recognized the value of social problem-solving as a positive coping skill and supported the need for: (i) having a structured method for evaluating parents orientations to and definitions of problems, and (ii) training parents to have a positive attitude/orientation to problems; and to be skilled in defining problems.</p>

## Appendix E

### Focus group with speech-language therapists: informed consent form and biographical information sheet



UNIVERSITEIT VAN PRETORIA  
UNIVERSITY OF PRETORIA  
YUNIBESITHI YA PRETORIA  
Faculty of Humanities

Centre of Augmentative and Alternative Communication  
University of Pretoria  
Pretoria  
0002

#### Preamble for Focus Groups with Speech-Language Therapists

Thank you very much for volunteering to participate in this focus group discussion. *(The researcher and participants were familiar with each other, so there is no need for formal introductions).*

As you may know, I am currently conducting a research project looking broadly at parents' help-seeking skills during ECCI. You may be well aware that many parents are not happy with their children's intervention programmes as they feel it does not address the problems that parents experience at home. There are, of course, many reasons for this – but I am particularly interested in the role that two issues may play when parents' access help from speech-language therapists: (1) parents' perceptions of their child's disability, and (2) parents communication of the problems they experience in caring for their child, to the speech-language therapist.

Parents' unhappiness may arise because they are not coping with their child's disability, and this is not being addressed by the intervention programme; OR that they may not be defining the problem adequately to professionals, resulting in the selection of inappropriate therapy goals. I am also thinking about how we can support and train parents in both aspects, so that they cope better and are able to ask for the help they actually need.

The reason for me asking you to participate in this discussion, is that I am especially interested in *your ideas* about the topic, in relation to *your experiences* of working with parents. We will use the term "parent" to refer to the child's biological parent/s or caregiver. Over the next hour or so, I will ask you a few questions to stimulate discussion within the group. I will be audio-recording the discussion so that I can listen to it again, should I miss anything now. I'd like to reassure you that you will remain anonymous as group rather than individual responses would be analyzed, ensuring confidentiality of individual responses. Please try to speak one at a time, so that the recording is clear. I would really like each one of you to contribute to the discussion, as your experiences may not be the same. Please listen when others are speaking. There is no right or wrong answer, all your views (both positive and negative) are valuable, and you will not be judged by your opinions. You are also free to withdraw from the discussion without any penalty, if you are not comfortable at any stage. Once the audio-recordings are transcribed, you are welcome to contact me if you want to check the content.

If you are willing to participate and be recorded, please sign the consent form and then complete the information sheet. Enter the number that you have been given, where required. Thank you for your time.

Centre for Augmentative and Alternative Communication (CAAC)  
Sentrum vir Aanvullende en Alternatiewe Kommunikasie (SAAK)  
Communication Pathology Building  
University of Pretoria, Lynnwood Road  
PRETORIA, 0002  
Republic of South Africa

Fax/Faks: +27 86 510 0841  
Tel: +27 12 420 2001

[juan.bornman@up.ac.za](mailto:juan.bornman@up.ac.za)  
[www.caac.up.ac.za](http://www.caac.up.ac.za)

Participant's name: \_\_\_\_\_ Participant's number: \_\_\_\_\_

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

Principal investigator: Legini Moodley  
Research Supervisor: Professor Kitty Uys

I understand the information provided about the study. If I have any questions or concerns, I can call the Principle Investigator, Legini Moodley at 0724779767 at any time.

I understand my rights as a participant, and I voluntarily consent to participate in this study. I will receive a signed copy of this consent form.

Signature of Participant \_\_\_\_\_ Date \_\_\_\_\_

Signature of Investigator \_\_\_\_\_ Date \_\_\_\_\_

Signature of Supervisor \_\_\_\_\_ Date \_\_\_\_\_

**Biographical Information Sheet: Focus Group with Speech-Language Therapists**

a) Participant number: .....

b) Male or Female: .....

c) Number of years of work experience:.....

d) Years of experience working with parents of young children (0-6years).....

e) Place of work: *(please tick)* Public hospital ..... Other:.....



\_\_\_\_\_  
Ms Legini Moodley  
PhD Student: CAAC

\_\_\_\_\_  
Prof Kitty Uys  
Supervisor: CAAC

Centre for Augmentative and Alternative Communication (CAAC)  
Sentrum vir Aanvullende en Alternatiewe Kommunikasie (SAAK)  
Communication Pathology Building  
University of Pretoria, Lynnwood Road  
PRETORIA, 0002  
Republic of South Africa

Fax/Faks: +27 86 510 0841  
Tel: +27 12 420 2001

[juan.bornman@up.ac.za](mailto:juan.bornman@up.ac.za)  
[www.caac.up.ac.za](http://www.caac.up.ac.za)

## Appendix F

### Detailed results of focus group discussion with parents

CATEGORY	DESCRIPTION
<b>Participants</b>	Six parents from one of the hospitals volunteered to participate in the focus group, and met the researcher at the hospital as the venue was suitable. These participants were excluded from the main study. The participants' transport costs were paid for by the researcher. A research assistant (community service speech-language therapist) was present to assist with audio-recording. The participants were introduced to each other. Three parents were familiar with each other, but all established rapport quite easily, contributing to an informal and non-threatening conversational context.
<b>Aims</b>	To explore parents' perceptions of their experiences when communicating their problems to speech-language therapists during ECCI, The following questions were asked to stimulate discussion on the topic: <ol style="list-style-type: none"> <li>(i) How do you feel about your child's communication and other disabilities?</li> <li>(ii) How do you feel when you have to talk about your problems to health care professionals?</li> <li>(iii) How well do you feel you describe your problems so that professionals have a good understanding of it? Rate as: Very well – Good—Okay –Not so well</li> <li>(iv) Drawing from your experiences, do you think that you would benefit from training to help you cope better, and to help you talk to professionals about your problems in ways that help them understand better?</li> <li>(v) Are you currently receiving any support or training from the hospital to help <i>you</i> cope better with the challenges you face during parenting?</li> <li>(vi) Would you be willing to attend training and support programmes to help you cope better, and which also help you to talk to professionals about your problems in a better way?</li> <li>(vii) I plan on developing a parent training programme. How many hours of training would be suitable for you to attend, per week, if you could access such a programme?</li> </ol>
<b>Method</b>	As discussed in the detailed information regarding the focus groups as seen in Appendix D. For the information given to parents and biographical information sheet, refer to Appendix G.
<b>Analysis</b>	As discussed in Table 4
<b>Results</b>	A summary of the key issues that emerged from the focus group included: <i>Question (i):</i> Some parents reported feeling overwhelmed, whilst others said that they were still trying to come to terms with their child's disability. Parents of older children (4-6yrs) said that they felt a little better after their children commenced with ECCI. Many parents reported feeling guilty, and not in control of the situation. <i>Question (ii):</i> All parents reported feeling very intimidated when they first made contact with professionals, especially those with limited education and who did not speak English as a first language. They felt more comfortable when professionals were friendly and easy to talk to. The behaviour of the professional affected the nature and amount of information that they voluntarily shared with him/her. They found it difficult to talk openly to someone who did not show any understanding of their situation. Two parents said that they did not provide all the information that they knew as they were struggling to accept their child's disability, and thus chose to see if the therapist asked any specific questions. One parent felt that professionals are very busy, and she did not want to take up too much of their time by giving too much of information. <i>Question (iii):</i> Three parents said "okay" and three said "not so well", generally reflecting limited confidence in their problem definition skills. <i>Question (iv):</i> All parents said that parents would benefit. <i>Question (v):</i> Most parents indicated that they were not attending any specific training programme, but received support and information from therapists during individual and/or group therapy sessions for their child. However, not much was directed at developing or

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enhancing their coping and help-seeking skills, and none focused on their problem definition skills.

*Question (vi-vii):* All parents indicated their willingness to attend, although they did raise the following issues as possible barriers: duration of training (training had to be short, for example, 2-3½ hours at the most once a week; many agreed that a 3-4 week period was manageable but if it was longer then participation may be problematic), timing of training (parents who were working preferred training to be given on weekends, whilst those at home preferred week-days); transport costs for attending, care-giving arrangements for their child.

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**Implications**

Parent responses highlight the need for promoting help-seeking with respect to positive orientations and problem definition skills. In addition, parents indicated a need for parent support with respect to (i) coping positively with a child with a disability, and (ii) improving their skills in communicating problems so that they provided organized and relevant information to professionals.

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## Appendix G

### Focus group with parents: informed consent form and biographical information sheet



UNIVERSITEIT VAN PRETORIA  
UNIVERSITY OF PRETORIA  
YUNIBESITHI YA PRETORIA  
Faculty of Humanities

Centre for Augmentative and Alternative Communication  
University of Pretoria  
Pretoria  
0002

#### Preamble for Focus Groups with Parents

Thank you very much for agreeing to participate in this focus group discussion. I am Legini Moodley, a speech-language therapist who is currently registered for a Phd programme with the University of Pretoria.

As parents of young children with disabilities, you face many challenges and you need to be skilled in dealing with them. There are times when you may find that you are not getting the help you need from professionals. I am doing a study that looks at how you approach the problems that you experience parenting your child, and how you communicate these problems to health care professionals, such as speech-language therapists. Both issues may contribute to your success or failure in getting the help that you need.

Over the next hour or so, I will ask you some questions and you can discuss it within the group. I am really interested in *your ideas* and *your experiences* in managing your life and your child's disability. I will be tape-recording the discussion so that I can listen to it again, should I miss anything now. I'd like to reassure you that you will remain anonymous and no person's name will be used when I write up the study. The groups' responses will be taken, so individual responses remain confidential. Please try to speak one at a time, so that the recording is clear. I would really like each one of you to contribute to the discussion, as your experiences may not be the same. Please listen when others are speaking. There is no right or wrong answers as all your views (both positive and negative) are valuable and you will not be judged by your opinions. You are also free to withdraw from the discussion without any penalty, if you are not comfortable at any stage. Once the taped-recordings are transcribed, you are welcome to contact me if you want to check the content.

If you are willing to participate and be recorded, please sign the consent form. Thereafter complete the information sheet that will be handed out to you. We will go through it together so that you know what to do. If you need any assistance, please raise your hand and I will come to you. Thank you.

Centre for Augmentative and Alternative Communication (CAAC)  
Sentrum vir Aanvullende en Alternatiewe Kommunikasie (SAAK)  
Communication Pathology Building  
University of Pretoria, Lynnwood Road  
PRETORIA, 0002  
Republic of South Africa

Fax/Faks: +27 86 510 0841  
Tel: +27 12 420 2001

[juan.bomman@up.ac.za](mailto:juan.bomman@up.ac.za)  
[www.caac.up.ac.za](http://www.caac.up.ac.za)

**Informed Consent Form**

Participant's name: \_\_\_\_\_ Participant's number: \_\_\_\_\_

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

Principal investigator: Legini Moodley  
Research Supervisor: Professor Kitty Uys

I understand the information provided about the study. If I have any questions or concerns, I can call the Principle Investigator, Legini Moodley at 0724779767 at any time.

I understand my rights as a participant, and I voluntarily consent to participate in this study. I will receive a signed copy of this consent form.

Signature of Participant \_\_\_\_\_ Date \_\_\_\_\_

Signature of Investigator \_\_\_\_\_ Date \_\_\_\_\_

Signature of Supervisor \_\_\_\_\_ Date \_\_\_\_\_

**Biographical Information Sheet: Focus group with Parents**

- a) Participant number: \_\_\_\_\_
- b) Mother or Father: *(please tick)* **Mother** \_\_\_\_\_ **Father** \_\_\_\_\_
- c) Age: \_\_\_\_\_
- d) Highest educational level: \_\_\_\_\_
- e) Is English your first language? *(please tick)* **Yes** \_\_\_\_\_ **No** \_\_\_\_\_
- f) The family's total monthly income: \_\_\_\_\_
- g) Child's age: \_\_\_\_\_
- h) Child's disability: \_\_\_\_\_
- i) Describe your health status: *(please tick)* **Excellent** \_\_\_\_\_ **Good** \_\_\_\_\_ **Fair** \_\_\_\_\_ **Poor** \_\_\_\_\_



\_\_\_\_\_  
Ms Legini Moodley  
PhD Student: CAAC

\_\_\_\_\_  
Prof Kitty Uys  
Supervisor: CAAC

Centre for Augmentative and Alternative Communication (CAAC)  
Sentrum vir Aanvullende en Alternatiewe Kommunikasie (SAAK)  
Communication Pathology Building  
University of Pretoria, Lynnwood Road  
PRETORIA, 0002  
Republic of South Africa

Fax/Faks: +27 86 510 0841  
Tel: +27 12 420 2001

[juan.bormman@up.ac.za](mailto:juan.bormman@up.ac.za)  
[www.caac.up.ac.za](http://www.caac.up.ac.za)

## Appendix H

### Development of the Problem Orientation Questionnaire

Table H1  
*Development of the Problem Orientation Questionnaire*

Section	Cognitive Variable & Process Dimension	Question #	Total # of questions	Question Area	Type of Question	Motivation
A	Problem Perception  Value	A1	3	<i>Recognition/ awareness of a communication problem</i> <i>Q: Do you think that your child's communication is a problem?</i>	Closed ended 4 options	<p><i>Adaptation:</i> The PSSM form requires respondents to identify a problematic question, but does not include any questions on their recognition of the problem. However, it is important for speech-language therapists to determine whether parents recognize/are aware of their child's communication difficulties. The latter reflects the value placed on communication skills, and has implications for parents' active participation during ECCI (Lazarus &amp; Folkman, 1984; D'Zurilla, 1986; D'Zurilla &amp; Nezu, 2010; Rossetti, 2001). The need for parent support is also highlighted.</p> <p>D'Zurilla (1986, p. 22) states that "sensitivity to problems is an important prerequisite for effective problem solving because it sets the occasion for problem solving activity". Thus, in order for to manage their child's communication difficulties appropriately by seeking ECCI services, they must be able to <i>recognize</i> when their child's communication development is not like other children of similar age, in the community.</p>
		A2		<i>Value of communication</i> <i>Need for ECI</i> <i>Q: Do you think that your child's communication needs treatment?</i>	Closed ended 3 options	<p>For positive perceptions, recognition of a problem is not sufficient to solving it (D'Zurilla, 1986; D'Zurilla &amp; Nezu, 1999, 2010), the individual must be forced to cope with it in an active, direct manner (rather than deny or ignore it). Therefore, parents must also recognize that they do not possess the knowledge and/or skills to help their child develop age-appropriate</p>

Section	Cognitive Variable & Process Dimension	Question #	Total # of questions	Question Area	Type of Question	Motivation
						communication skills, and consequently see the need for accessing ECCI services.
		A3		<i>Degree of importance placed on ECCI</i> <i>Q: How important do you think it is to have your child's communication problems treated?</i>	4 point rating scale ranging from extremely important to not at all important	It is important for parents to understand the following regarding the importance of communication skills: (i) Cognitive, communicative, motor, and psycho-social domains of development are highly interdependent during early childhood development, and intervention efforts directed to any one area is likely to influence other areas as well (American Speech-Language-Hearing Association, 2008), and (ii) any delay that influences an infant's early communication acquisition is likely to have a significant impact on the infant's later social, academic, and vocational achievements ( Rossetti, 2001)
B	Problem Attribution  <i>Belief</i>		2			<i>Adaptation:</i> The PSSM form does not distinguish between the initial and maintaining cause of the problem. During ECCI, it is important for parents to distinguish between the two causes, as it may not necessarily be the same. especially in the case of children's communication disabilities. This has implications for parents' orientation toward their child's communication disability.
		B1		<i>Perception of initial cause of the communication problem</i> <i>Q: What do you think caused your child's communication difficulties right from the beginning?</i>	4 options including "I'm not sure"	A facilitative /positive problem attribution style involves attributing the cause to environmental factors and/or relatively benign, transient or changeable personal factors rather than some stable personality abnormality or defect (D'Zurilla, 1986, p. 23). However, in the case of a child with an established risk factor, there is often a stable organic factor resulting in the disability and

Section	Cognitive Variable & Process Dimension	Question #	Total # of questions	Question Area	Type of Question	Motivation
						mediating the child's prognosis. It is <i>because</i> of the latter that it is critical for parents to have a facilitative/positive problem attribution style in order to remain optimistic and utilize positive problem solving skills by seeking ECCI services (Peterson & Steen, 2002; D'Zurilla, 1986; D'Zurilla & Nezu, 1999, 2010).
		B2		<i>Perception of maintaining cause of the communication problem</i> <i>Q: What do you think keeps your child's communication the way it is – does not allow it to improve?</i>	4 options including "I'm not sure"	The stable factor contributing to the child's established risk may always maintain the disability. However, it is also important to identify what the child's communication development potential is, despite the established risk factor, as other physical and social environmental factors may hinder the child's ability to reach this potential. For example, parent's overprotection, decreased financial resources to access ECCI, etc. This information can assist planning during ECCI.
C	Problem Appraisal Value	C1	1	<i>Perception of communication difficulty</i> <i>Q: Which of the following statements describe how you see your child's communication difficulty: a threat, or a challenge?</i>	Closed ended 4 point-rating scales ranging from very threatening to very positive challenge	<i>Adaptation:</i> The PSSM form evaluates problem appraisal of threat and challenge separately in two questions. In this measure, both concepts were combined and occupied opposite ends of the rating scale.  It is important for the parent to view the child's communication disability as a challenge or opportunity for further personal growth, rather than a threat. The former view will encourage the parent to initiate effortful help-seeking behaviours to access ECCI services (D'Zurilla, 1986; D'Zurilla & Nezu, 1999, 2010)
D	Personal control:  2 components  ▪ <i>outcome expectancy</i>	D1	6	<i>Perception of outcome expectancy</i> <i>Q: When you first noticed that your child's communication</i>	4 point rating scale ranging from very sure to very unsure	<i>Adaptation:</i> The PSSM form only evaluates personal control with respect to the respondents' initial recognition of the problem. As parents' commencement of ECCI services may differ from the time of initial recognition of the problem, it

Section	Cognitive Variable & Process Dimension	Question #	Total # of questions	Question Area	Type of Question	Motivation
	<i>Belief</i>			<i>was a problem – how sure did you feel that these problems could be improved with treatment?</i>		<p>was important to ascertain their initial and current perceptions of personal control toward their child’s communication disability, with respect to outcome expectancy (2 questions) and self-efficacy expectancy (4 questions).</p> <p>Bandura (2001) states that perceived outcome and self-efficacy expectations were found to reduce anxiety and facilitate adaptive coping in stressful situations. It is therefore important for parents to believe that help through ECCI will assist them in managing their child’s communication disability (outcome expectancy).</p>
		D2		<p><i>Perception of outcome expectancy</i>  <i>Q: How sure do you currently feel that your child’s communication can be improved with appropriate treatment?</i></p>	4 point rating scale ranging from very sure to very unsure	
	<p>▪ <i>self efficacy expectancy</i></p> <p><i>Belief</i></p>	D3		<p><i>Perception of self efficacy</i>  <i>Q: When you first noticed that your child’s communication was a problem, how confident did you feel in your ability to help him/her – by using your own knowledge and skills?</i></p>	4 point rating scale ranging from very confident to not confident	Parents must also believe that through their own efforts such as talking to family, community members etc, they are capable of accessing the help they need from ECCI services (self-efficacy expectations).
		D4		<p><i>Perception of Self Efficacy</i>  <i>Question: Currently, how confident do you feel in your ability to help</i></p>	4 point rating scale ranging from very confident to not confident	

Section	Cognitive Variable & Process Dimension	Question #	Total # of questions	Question Area	Type of Question	Motivation
				<i>him/her – by using your own knowledge and skills?</i>		
		D5		<i>Perception of Self Efficacy Q: When you first noticed that your child's communication was a problem, how confident did you feel in your ability to get help from professionals and family members?</i>	4 point rating scale ranging from very confident to not confident	
		D6		<i>Perception of Self Efficacy Q: Currently, how confident do you feel in your ability to get help from professionals and family members?</i>	4 point rating scale ranging from very confident to not confident	
E	Time and Effort  2  i) Parent's estimate of time and effort required to improve communication  Belief	E1	2	<i>Parents' expectations  Parents' estimate of time and effort required to see improvement in communication Q: How much of your time and effort do you think it will take on your part to see some improvement in your child's communication skills (even if improvement is very little).</i>	Closed ended ranging from "a lot of time and effort" to "no time at effort at all"	Parents' expectations regarding improvements in communication must be realistic and informed by the severity of the disability. These expectations in turn will influence parents estimates of the time and effort required to see improvements in the child's communication skills. Unlike motor skills which are easily seen, improvements in underlying communication skills (eg. attention) may be more difficult to recognize, and may develop at a slower pace. It is therefore important for parents to be informed and counseled on communication development in order for them to have a realistic estimate of time and effort required. It is also important for parents to persist in giving off their time and effort, in the face of obstacles and disappointments when progress is highly likely but not immediately

Section	Cognitive Variable & Process Dimension	Question #	Total # of questions	Question Area	Type of Question	Motivation
						forthcoming (D’Zurilla, 1986; D’Zurilla & Nezu, 1999, 2010). On the other hand, when progress is limited by the severity of the disability, parents’ estimate of time and effort must be realistic.
	ii) Parents’ willingness to devote time and effort to helping their child  Value	E2		Parents’ willingness to devote time and effort to helping their child Q: How much of time and effort are you willing to put into helping your child improve his/her communication skills – knowing that improvement (even if very little) may be possible?	Closed ended ranging from “a lot of time and effort” to “no time at effort at all	Active parent involvement is an important factor that promotes the efficacy of ECCI (Rossetti, 2001). The parent’s recognition of the value of communication skills, the efficacy of ECCI, as well as an enabling intervention environment will encourage parents to be persistent despite the presence of challenging circumstances (D’Zurilla, 1986; Dunst et al., 1994). In some cases, work or other commitments may prevent parents from personally attending intervention. Nevertheless, the parents’ willingness to explore other methods of accessing intervention is important. For example, sending the child with a trusted family member who can implement therapy methods at home and /or ensure that parents understand what needs to be done /monitored in the home programme given. .

[adapted from *The Problem-Solving Self Monitoring (PSSM) method proposed by D’Zurilla (1986, p. 236)*]

Note: Q = Question

Table H2

*Overview of questions per dimension of problem orientation domain*

Five dimensions of problem orientation	Number of questions
A. Problem perception	3
B. Problem Attribution	4
C. Problem Appraisal	1
D. Personal Control	8
E. Time and Effort	3
	Total = 19

## Appendix I

### Analysis & Interpretation of Problem Orientation Questionnaire

#### 1. Data analysis:

Table I1 describes the process that was followed to develop a continuum of parents' orientation functioning, ranging from positive to negative.

Table I1

*Development of the data analysis process*

Steps in data analysis	Statistical procedures and calculations
<b>Establish cut-off score that differentiates parents' positive orientation from negative orientation. A four-point scoring system was used with highest score = 4 and lowest score = 1.</b>	Calculate <i>range</i> of parents' scores (i.e. measure of variability), and the <i>median</i> within the range (i.e. measure of central tendency) <i>Calculation:</i> (Hinkle, Wiersma & Jurs, 1982) $Range = (highest\ score - lowest\ score) + 1 = (4 - 1) + 1 = 4$ $Median\ score = (N + 1) / 2 = (4 + 1) / 2 = 2.5$ <i>Application:</i> score of 2.5- 4.0 = range of positive orientation 2.4-1.0 = range of negative orientation
<b>Establish intervals to classify parents' orientations within the positive and negative range. Class intervals must be sensitive to any change in parents' orientations after training.</b>	The following <b>four class intervals</b> were selected: <i>Positive continuum:</i> slightly positive, moderately positive, largely positive, positive <i>Negative continuum:</i> slightly negative, moderately negative, largely negative, negative
<b>Correlate the four intervals of positive and negative functioning with the four-point scoring system.</b>	Scores of 1 and 4 indicate negative and positive orientations respectively. Equal class intervals between the median and the lowest and highest scores were calculated, to classify scores as: largely, moderately and slightly negative and positive. <i>Calculation:</i> Class intervals on the positive continuum: $(highest\ score - median\ score) / 3\ interval\ sets$ $(3.9 - 2.5) / 3 = 1.4 / 3 = 0.46 = 0.5$ Class intervals on the negative continuum: $(median\ score - lowest\ score) / 3\ interval\ sets$ $(2.5 - 1.1) / 3 = 1.4 / 3 = 0.46 = 0.5$

For each question, pre-and post-training scores of the experimental and control groups were analysed using the descriptions of class intervals within the positive or negative range. Conclusions regarding each group's functioning on each of the five dimensions were derived using descriptive analysis of *individual items*, in line with the use of an ordinal scale of measurement (Leedy & Ormrod, 2013; McMillan & Schumacher, 2010). Limited empirical information on the theoretical properties of the five dimensions of the construct constrained analysis beyond the individual item level (for example, at the dimension or overall construct levels).

#### 2. Interpretation of scores on Problem Orientation Questionnaire

Table I2 outlines the guidelines that were used to interpret parents' scores for individual items in the five dimensions of problem orientation. The guidelines were derived from the theoretical framework of problem orientation and definition outlined in Table 1, section 2.3 in Chapter 2.

Table I2  
*Guidelines to interpret parents' problem orientation scores*

Actual Score	Interpretation	Implication for help seeking in ECCI
4.00	positive orientation	Orientation will have a <i>very positive effect</i> in motivating the parent to seek help from professionals.
3.5-3.9	largely positive orientation	Orientation will have a <i>largely positive effect</i> in motivating the parent to seek help from professionals. However, there are <i>one or two areas</i> where negative perceptions are present, which may hinder the parent from seeking help. Parent support in identifying and managing these areas is recommended.
3.0-3.4	moderately positive orientation	Orientation will have a <i>moderately positive effect</i> in motivating the parent to seek help from professionals. However, there are <i>a few areas</i> where negative perceptions are present, which are likely to hinder the parent from seeking help. Parent support in identifying and managing these areas is strongly recommended.
2.5-2.9	slightly positive orientation	Orientation will have a <i>slightly positive effect</i> in motivating the parent to seek help from professionals. There are a <i>fair number of areas</i> where negative perceptions are present, which are very likely to hinder the parent from seeking help. Parent support in identifying and managing these areas is strongly recommended.
2.0-2.4	slightly negative orientation	Orientation will have a <i>slightly negative effect</i> in motivating the parent to seek help from professionals. There are a <i>number of areas</i> where negative perceptions are present, which hinder the parent from seeking help. Parent support in identifying and managing these areas is strongly recommended to enable parent to develop positive help-seeking behaviours.
1.5-1.9	moderately negative orientation	Orientation will have a <i>moderately negative effect</i> in motivating the parent to seek help from professionals. There are <i>many areas</i> where negative perceptions are present, which hinder the parent from seeking help. Parent support in identifying and managing these areas is strongly recommended to enable parent to develop positive help-seeking behaviours
1.1-1.4	largely negative orientation	Orientation will have a <i>largely negative effect</i> in motivating the parent to seek help from professionals. Parent has negative perceptions in <i>most areas</i> , which greatly hinders help-seeking. Parent support in identifying and managing these areas is strongly recommended to enable parent to develop positive help-seeking behaviours.
1	negative orientation	Orientation will have a <i>negative effect</i> in motivating the parent to seek help from professionals. Parent has negative perceptions in <i>all areas</i> , which significantly hinders help-seeking. Parent support in identifying and managing these areas is strongly recommended to enable parent to develop positive help-seeking behaviours.

\***Note:** Parent support refers to appropriate education and counselling

## Appendix J

### PROBLEM ORIENTATION QUESTIONNAIRE

#### INSTRUCTIONS

I am going to read 19 statements that describe the way parents' may feel about their child's talking. Please tell me which statement best describes your feelings about your child's talking.

*(Procedure: A copy of the table in font size 14 is presented to the parent. The interviewer reads each statement and the response options given. Only after the parent has indicated her/his choice from the alternatives, will the interviewer move to the next statement).*

	Dimensions of Parents' Orientations to Problems	Score		
<b>A</b>	<b>Problem Perception (recognition of problem and need for a solution)</b>			
<b>A1</b>	<b>Recognition of a communication problem</b>			
	<b>Do you think that your child's "talking" is a problem?</b>			
	My child's talking is <i>definitely a problem</i> .	4		
	My child's talking <i>seems to be a problem</i> .	3		
	<i>I'm really not sure</i> whether my child's talking is a problem.	2		
	My child's talking <i>is not a problem</i> .	1	<b>V 32</b>	
<b>A2</b>	<b>Need for Early Childhood Communication Intervention</b>			
	<b>Do you think that your child needs treatment to talk better?</b>			
	My child <i>definitely needs treatment</i> to talk better.	4		
	<i>I'm not sure, my child may need</i> treatment to talk better.	3		
	<i>I'm not sure, my child may not need</i> treatment to talk better	2		
	My child <i>definitely does not need treatment</i> , s/he talks well.	1	<b>V33</b>	
<b>A3</b>	<b>Importance placed on communication skills</b>			
	<b>How important do you think it is to treat your child's talking problems?</b>			
	Very important	4		
	Important	3		
	Slightly important	2		
	Not at all important	1	<b>V34</b>	
<b>B</b>	<b>Problem Attribution (locus of causality – internal/external)</b>			
	<i>[Parent's responses to B1 &amp; B4 must be rated by the examiner]</i>			
<b>B1</b>	<b>Initial cause of the communication problem</b>			
	<b>Look back to the time your child was born. What do you think caused him/her to have a problem with talking?</b>			
	<i>Write down and rate parent's response:</i>			
	Factors that were beyond anyone's control (solely external, nobody to blame) <i>For example: it's God's will, he was born sick, I cannot blame anyone</i>	4		
	Factors attributed to parent or other people's actions. <i>Parent has accepted</i> the initial cause and moved forward /or is in the process of moving forward in working through the situation. <i>For example (parent): I was too old/ I was sick and took medication during my pregnancy etc but I now need to help my child</i> <i>For example (other people): Nurses/doctors were negligent. It is upsetting but I don't want to dwell on it.</i>	4		

Dimensions of Parents' Orientations to Problems		Score		
	Factors attributed to the parent or other people's actions, or cultural beliefs that hinder positive coping. Parent has not come to terms with the situation. <i>For example (parent/other peoples' actions): I was too old to have a child – I should have known better; Nurses/doctors negligence.</i> <i>For example (beliefs): My father cursed me when I fell pregnant.</i>	1		
	I am not sure (reflecting confusion)	2	V35	
<b>B2</b>	To what extent do you blame yourself, other people or other circumstances for causing the communication disability? Do you think ...			
	It was <i>totally</i> my fault (solely internal)	1		
	It was <i>largely</i> my fault (mostly internal)	2		
	It was <i>largely due to other people or circumstances.</i> (mostly external)	3		
	It was <i>totally</i> due to factors beyond anyone's control.(solely external)	4	V36	
<b>B3</b>	<b>Effect of established disability on communication disability</b> What effect will ( <i>state initial cause</i> ) have on your child's learning, if s/he is given treatment to talk properly? Do you think ...			
	It will affect all areas of my child's development that are important for learning. <i>No matter what treatment</i> we give her/him, s/he <i>will never be able to learn</i> to talk properly. ( <i>global &amp; stable effect</i> )	1		
	It will affect all areas of my child's learning. <i>Treatment may help, but not very much.</i> ( <i>somewhat global &amp; stable effect</i> )	2		
	It will affect some areas of my child's learning and <i>treatment may help</i> her/him learn to talk. ( <i>somewhat specific &amp; unstable effect</i> )	3		
	It will affect some areas of my child's learning, but <i>treatment will find ways of helping her/him to talk</i> as best as s/he can. ( <i>unstable effect</i> )	4	V37	
<b>B4</b>	<b>Maintaining cause of the communication problem</b> <b>Look at your child now. What do you think makes it difficult for him/her to talk in the best way that s/he can, even though s/he was born with ----(state name of established disability)?</b> <i>Write down and rate parent's response:</i>			
	Factors internal or external to the child that are <b>not amenable to treatment</b> (body structure and functioning, communication related activities, participation) <i>For example: Her mind is slow; the disability, tongue is not working properly etc</i>	1		
	<b>Factors internal to the child that that are amenable to treatment</b> ((body structure and functioning; communication related activities, participation) <i>For example: she does not have enough words (vocabulary), but can learn; he does not know how to say the words , he needs more therapy – once a month is not enough, she is shy, his behaviour problems etc</i>	4		

Dimensions of Parents' Orientations to Problems		Score		
	<b>Factors external to the child</b> (social, physical, financial etc) that are <b>amenable to treatment</b> . Relates to parents, family, school, money, home etc. <i>For example: I am overprotective/scared, so I don't allow him to do things for himself; I anticipate his needs and there is no need for him to talk.</i>	4		
	I'm not sure	2	V38	
<b>C</b>	<b>Problem Appraisal</b>			
<b>C1</b>	<b>Which of the following statements describe how you see your child's communication difficulty. It is ...</b>			
	<b>Stressful</b> for me, my child and my family <i>For example: It has a great impact on my health, makes me feel depressed /anxious; affects my family; will affect my child's learning, and interaction with people.</i>	1		
	<b>Slightly stressful</b> to me, my child and my family <i>For example: It has some impact on my health; my child's learning; on my family, etc.</i>	2		
	<b>A little stressful, but also a challenge</b> to see what I can do to help <i>For example: I'm worried, but also feel that I can do something to help the situation.</i>	3		
	<b>A positive experience</b> that makes me a better person. I can learn about the disability and help my child and others. <i>For example: I can help other parents with children with similar problems by sharing my experience.</i>	4	V39	
<b>D</b>	<b>Personal control</b>			
	<i>Outcome expectancy</i>			
<b>D1</b>	<b>How sure do you feel that your child's talking can be improved with treatment?</b>			
<b>D1</b>	Very sure	4		
	Sure	3		
	Unsure	2		
	Very unsure	1	V40	
<b>D2</b>	<b>Self Efficacy</b>			
	<i>How confident do you feel to use your own knowledge and skills to help him talk better?</i>			
	Very confident	4		
	Confident	3		
	Slightly confident	2		
	Not confident	1	V41	
<b>D3</b>	<b>How confident do you feel to ask family and friends for help?</b>			
	Very confident	4		
	Confident	3		
	Slightly confident	2		
	Not confident	1	V42	
<b>D4</b>	<b>How confident do you feel to ask professionals for help?</b>			
	Very confident	4		
	Confident	3		
	Slightly confident	2		
	Not confident	1	V43	

Dimensions of Parents' Orientations to Problems		Score			
<b>E</b>	<b>E1</b>	<b>Commitment of Time and Effort</b> <i>Parents' estimate of time</i> <b>How much of time do you think it will take to help your child learn to talk better (even if improvement is very little)?</b>			
		A lot of time	4		
		Some time	3		
		Little time	2		
		No time at all	1		<b>V44</b>
	<b>E2</b>	<b>Parent's willingness to devote time and effort</b> <i>How much of time are you willing to give to help your child learn to talk better?</i>			
		All the time that I have	4		
		Some time	3		
		A little time	2		
		No time at all	1		<b>V45</b>
	<b>E3</b>	<b>How much of effort are you willing to make to help your child learn to talk better?</b>			
		A lot of effort	4		
		Some effort	3		
	A little effort	2			
	No effort at all	1		<b>V46</b>	

## Appendix K

### Problem Definition Question and Rating Scale

#### Problem Definition Question:

##### Instruction to parent:

Please tell me about the difficulties you have with your child’s talking, and what help you would like from the speech-therapist. I have not seen your hospital file and therefore don’t know anything about you or your child. Please give me all the information that *you think I should know*, in order for me to understand your difficulties and help you.

**Probe questions** will only be used to *obtain clarification* of information provided by the parent (e.g. unintelligible utterances), not to direct the parent to areas/topics that have not been covered or inadequately explained/described.

#### (a) Problem Definition Rating Scale:

Table K1

*Rating scale to measure parent’s definition of problems*

Problem Definition Indicators	Rating		
<p><b>1. Organization of information</b> (important for understanding the nature of the problem)</p> <p><b>Three dimensions:</b> a. what is the problem, to whom is it a problem and why? b. what changes / additions are desired, to whom and why. c. what obstacles prevent the development of desired</p>	<p><b>Organization of information is determined by assessing how well parents classify information into the three dimensions so that the nature of the problem can be understood (D’Zurilla, 1986, p. 29; Fiese et al., 1999).</b></p> <p><b>4 = Good Organization:</b> the parent describes the problem in a <i>very organized format (or very near to being organized)</i>. Information is clearly classified into the three components and presented in a very cohesive manner in more or less the order listed, resulting in a very meaningful description. This enables the SLP to obtain a <i>very good understanding</i> of the problem in all components.</p> <p><b>3 = Moderately Good Organization:</b> the parent describes the problem in a <i>somewhat organized format</i>. Information is appropriately classified into the three components, but is presented in a somewhat cohesive manner (i.e. description does not flow cohesively from one component to the next, thereby affecting meaning somewhat negatively). This results in the SLP obtaining a <i>somewhat good to fair</i> understanding of the problem. (i.e. some understanding in all components)</p> <p><b>2 = Moderately Poor Organization:</b> the parent describes the problem in a <i>disorganized format</i>. Information is classified appropriately into three or two components but is presented with limited</p>	<p><b>V47</b></p>	

Problem Definition Indicators	Rating		
communication behaviours	<p>cohesion between components and negative effect on meaning (i.e. disjointed presentation). This results in the SLT obtaining a <i>fair to limited</i> understanding of the problem</p> <p><b>1 = Poor Organization:</b> the parent describes the problem in a <i>very disorganized format</i>. Information is not classified appropriately in the components OR is generally appropriate, but presented in an extremely disjointed manner - resulting in a description that is not very meaningful. This results in the SLP obtaining a very <i>poor</i> understanding of the problem.</p>		
<p><b>2. Relevance of Information</b>            (includes factual and parent's perceptual information that is important for understanding the problem and planning intervention)</p>	<p>Relevance of the information is determined by assessing the following three sub-dimensions: specificity, use of concrete/operational terms, and comprehensiveness of the information. Relevance score is the mean of the three sub-dimension scores.</p> <p>Identify objective facts from assumptions, inferences and interpretations. Assumptions, inferences and interpretations must be checked and verified before it can be used to define and formulate the problem (D'Zurilla, 1986' D'Zurilla &amp; Nezu, 1999, 2010).</p> <p><b>4 = high relevance</b> - facilitates effective, sustainable ECCI planning  <b>3 = moderately high relevance</b> - somewhat facilitates effective, sustainable ECCI planning  <b>2 = moderately low relevance</b> - hinders effective, sustainable ECCI planning  <b>1 = low relevance</b> – severely hinders effective, sustainable ECCI planning</p>	V48	
<p><b>2.1 Specificity of information in each component - relating to the child's communication problem and/or other associated problems</b></p>	<p>The specific information must relate to the three components of the ICF framework (WHO, 2001):</p> <p>(i) <b>body structure and functioning</b> (e.g. articulators, cognitive skills, sensory skills, etc) ;</p> <p>(ii) <b>communication related activities</b> affected (e.g. intentionality, phonology, play, caregiver-child interaction, language comprehension, verbal and non-verbal language forms, oral motor abilities, sensory skills e.g. hearing and vision ( Rossetti, 2001);</p> <p>(iii) effects of the communication disability on the child's level of <b>participation</b> in the family's daily routine (i.e. inclusion or engagement in communication with the family during daily routines e.g. during meal-times/family chores; play; effect that child's limited participation has on caregiving, etc.)</p> <p><b>Other associated problems</b> relate to factors such as finance, social support and caregiver's health which are identified as restricting the family and child's ability to manage the communication disability.</p>	V49	

Problem Definition Indicators	Rating		
	<p><b>4 = Good Specificity:</b> description contains all or most of the information that is specific to the child’s communication disability and/or associated problems – thereby resulting in the SLT obtaining an <i>excellent</i> understanding of the problem</p> <p><b>3 = Moderately Good Specificity:</b> description contains a fairly large amount of the information that is specific to the child’s communication disability and/or associated conditions – thereby resulting in the SLT obtaining a <i>somewhat good</i> understanding of the problem</p> <p><b>2 = Moderately Poor Specificity:</b> description contains limited information that is specific to the child’s communication disability and/or associated conditions – thereby resulting in the SLT obtaining a <i>fair to vague</i> understanding of the problem</p> <p><b>1 = Poor Specificity:</b> description contains very limited information that is specific to the child’s communication disability and/or associated conditions – thereby resulting in the SLT obtaining a <i>very poor</i> understanding of the problem</p>		
<p><b>2.2 Use of “operational” or concrete terms</b></p>	<p><b>4 = Good use of operational terms:</b> Descriptions and/or explanations are drawn largely from the family’s daily life context and contain familiar words and terms. All or most descriptions/explanations include examples. This enables the SLT to obtain a <i>very good</i> understanding of the problem.</p> <p><b>3 = Moderately good use of operational terms:</b> Descriptions and/or explanations are drawn to a fair extent from the family’s daily life context and contain familiar words and terms. A fair number of examples are included. This enables the SLT to obtain a <i>somewhat good</i> understanding of the problem.</p> <p><b>2 = Moderately poor use of operational terms:</b> Descriptions and/or explanations are drawn from a limited part of the family’s daily life context. Familiar words and terms are used or used to some extent. A few examples are included. This results in the SLT obtaining a <i>fair to limited</i> understanding of the problem.</p> <p><b>1 = Poor use of operational terms:</b> Descriptions and/or explanations are drawn from a very limited part of the family’s daily life context, or not at all from this context. Very few familiar words and terms are used. Examples are very limited or not present at all. This results in the SLT obtaining a <i>very poor</i> understanding of the problem.</p>	<p><b>V50</b></p>	
<p><b>2.3 Comprehensiveness</b></p>	<p>Table K2 expands on the comprehensive nature of the information required in the three components.</p>	<p><b>V51</b></p>	

Problem Definition Indicators	Rating		
<i>of information in each component</i>	<p><b>4 = High Comprehensiveness:</b> Information provided in the component is <i>very comprehensive</i> - resulting in the SLT obtaining an excellent understanding of that component of the problem</p> <p><b>3 = Moderately High Comprehensiveness</b> Information provided in the component is <i>almost comprehensive</i> information - resulting in the SLT obtaining a somewhat good understanding of the that component of problem</p> <p><b>2 = Moderately Low Comprehensiveness:</b> Information provided in the component is sketchy – resulting in the SLT obtaining a <i>fair to limited</i> understanding of that component of the problem</p> <p><b>1 = Low Comprehensiveness:</b> Information provided in the component is extremely limited – resulting in the SLT obtaining a <i>very poor</i> understanding of that component of the problem</p>		

**Note:** Abbreviation: SLT=speech-language therapist

**(b) Information required for description to be comprehensive**

Table K2

*Information required for description to be comprehensive*

Three dimensions of Problem Definition	Information that needs to be contained in each component
(a) What present conditions are unacceptable, to whom & why	<p>The parent needs to identify the following: What is the problem? Who finds the child's communication behaviour and/or situation problematic? Why is it a problem? The description needs to outline the (i) <i>onset</i>, (ii) <i>progression</i>, and (iii) <i>current status</i> of the child's communication problem and/or associated problems. Information regarding the communication behaviours need to be described in relation to the parenting tasks implemented in the role of caregiver. Descriptions need to explain expectations, which are derived from the family's socio-behavioural (eco-cultural) values and beliefs.</p> <p>The parent should acknowledge if there are any gaps in/ missing information e.g. results from any other assessments; poor knowledge about something (e.g. developmental milestones)</p>
(b) What changes or additions to the present conditions are desired, by whom & why	<p>What would the parent like the situation to be, and why?</p> <p>The parent needs to describe the communication behaviours that s/he desires in the child. These communication behaviours may require changes and additions to the current behaviours so that s/he can implement the role of caregiver, in line with socio-cultural values and beliefs.</p>
(c) What obstacle(s) currently (i) reduces the child's ability to communicate effectively, and/or (ii) reduces the parent's ability to meet the demands imposed by the child's communication disability	<p>Parent's description of emotional obstacles (e.g. attitude towards child's disability, mental health difficulties), information (knowledge) deficits, skill deficits, conflicting demands (demands from other children, spouse, family, work, etc.).</p>

**Note:** For effective problem resolution, information in all three dimensions *should be provided spontaneously* by the help-seeker (D'Zurilla, 1986).

Thus, if a parent is skilled in problem definition, then information in all three components should be provided spontaneously, *without prompting/probing from the help-giver (SLT)*.

## Appendix L

### Data Capture and Rating Sheet for Problem Definition Question

<b>Participant No:</b>				
<b>Interview:</b> <i>(please circle)</i>	1	2	<b>Rater:</b> <i>(please circle)</i>	1      2

<b>1. Organization of Information.</b> <i>To what degree is the information organized logically and cohesively to facilitate the SLP's understanding of the problem?</i>				
<b>What is the problem? To whom is it a problem?</b>  	<b>Why is it viewed as a problem?</b>  	<b>Additions/changes that are desired? By whom &amp; why?</b>  	<b>Obstacles preventing</b> (i) the child from developing the desired communication behaviours  (ii) the parent from helping the child to learn to communicate	<b>V47</b>  Score
<b>2. Relevance of information.</b> <i>To what degree is the information relevant in each component to facilitate intervention planning?</i>				
	<b>A. Specificity of information to communication and associated conditions</b>	<b>B. Use of concrete/operational terms</b>	<b>C. Comprehensiveness of Information</b>	Score
<b>2.1 What is the problem? To whom is it a problem?</b>	<b>A. Body structure and function:</b>  <b>B. Communication related Activities</b> (intentionality, phonology, play, caregiver-child interaction, language comprehension, verbal and non-verbal language forms, oral motor abilities, sensory skills eg hearing and vision)	<b>Examples from the family's daily routine</b>	<b>Onset of the problem:</b>  <b>Progression; previous assessments</b>  <b>Current status of the problem:</b>  <b>Aspects not understood by the parent/gaps in information:</b>  <b>Relevant sociocultural information (e.g. expectations; beliefs; values)</b>	

	<b>A. Specificity of information to communication and associated conditions</b>	<b>B. Use of concrete/operational terms</b>	<b>C. Comprehensiveness of Information</b>	
	<b>C. Child's participation in the family's daily routine</b>			
	<b>D. Other associated problems:</b> feeding :  poverty/finance:  culture:  transport:  Mother's health:  Social support: Other:  Score	Score	Score	
<b>2.1.2 Why is the child's communication/other associated conditions a problem?</b>	Score	Score:	Score:	
	Average score <b>A1</b>	Average score <b>B1</b>	Average score <b>C1</b>	Average 2.1 <b>(A1+B1+C1)/3</b>

	<b>A. Specificity of information to communication and associated conditions</b>	<b>B. Use of concrete/operational terms</b>	<b>C. Comprehensiveness of information</b>	<b>Score</b>
<b>2.2. What changes are desired in the child's communication or other conditions? By whom?</b>	<b>A. Body structure and function:</b>  <b>B. Communication related Activities:</b> (intentionality, phonology, play, caregiver-child interaction, language comprehension, verbal and non-verbal language forms, oral motor abilities, sensory skills e.g. hearing and vision)	Examples from family's daily routine	Level of detail provided	
	<b>C. Child's participation in the family's daily routine</b>			
	<b>D. Other associated problems:</b> <b>feeding :</b> <b>poverty/finance:</b> <b>culture:</b> <b>transport:</b> <b>Mother's health/coping:</b> <b>Family support:</b> <b>Other:</b> <b>Score:</b>	<b>Score:</b>	<b>Score:</b>	

	<b>A. Specificity of information to communication and associated conditions</b>	<b>B. Use of concrete/operational terms</b>	<b>C. Comprehensiveness of information</b>	
2.2.2 Why are these changes desired?	Score:	Score:	Score:	
	Average score <b>A2</b>	Average score <b>B2</b>	Average score <b>C2</b>	<b>Average 2.2</b>
<b>3. What obstacles currently</b> (i) make it difficult for the child to learn to communicate effectively for his/her age level, and/or (ii) make it difficult for the parent to help the child improve his/her communication skills.	Child:  Parent:  <b>A3</b> Score:	    <b>B3</b> Score:	    <b>C3</b> Score:	    <b>Average 2.3</b>
	<b>Total score for Specificity: A</b> <b>A1+A2+A3 =</b>	<b>Total score for level of Concrete Information: B</b> <b>B1+B2+B3 =</b>	<b>Total score for Comprehensiveness: C</b> <b>C1+C2+C3 =</b>	
	<b>Final score A</b> (Total score/3) <b>V48</b>	<b>Final score B</b> (Total score/3) <b>V49</b>	<b>Final score C</b> (Total score/3) <b>V50</b>	
<b>Final Score: Relevance of information</b> <i>average of 3 final scores: (A+B+C)/3</i>	<b>V51</b>			
<b>Final Problem Definition Score:</b> Organization (O) + Relevance (R) of information divided by 2. Equal Weighting of the 2 variables (O & R)	<b>V52</b>			

## Appendix M

### Analysis and Interpretation of Problem Definition Question

#### 1. Data analysis

- Data were analysed for the two dimensions of problem definition, that is, organization of information and relevance of information. The dimensions were considered equally important in facilitating professionals' understanding of problems and were thus weighted equally.
- Parents' descriptions of problems and needs were transcribed from the audio-recordings and captured in Appendix L. Scores were assigned as follows:
  - (i) **organization of information:** a score was derived using the rating scale in Appendix K.
  - (ii) **relevance of information:** a score was derived for each of the three sub-dimensions (i.e. specificity, concrete/operationalization and comprehensiveness of information), using Appendix K. The sub-dimensions were considered equally relevant in facilitating professionals' understanding of the problem and thus weighted equally. Thus, the mean score for the three sub-dimensions was calculated. The mean score provided an overall score for the dimension (i.e. relevance of information).
    - The mean score for the two dimensions was calculated to provide a final score for parents' problem definition (see Appendix AK)
    - Pre-and post-training final scores for problem definition in the experimental and control groups were calculated and compared to determine the effect of training.
    - The development of the scoring system for the Problem Definition Question followed the same process as outlined for the Problem Orientation Questionnaire in Appendix I (see Table II). Scores ranged from excellent (score of 4) to poor (score of 1).

#### 2. Interpretation of scores on Problem Definition Question

- Table M1 below provides the guidelines that were used to interpret the final score of parents' problem definition. The guidelines were derived from the theoretical framework of problem orientation and definition in Table 1, section 2.4 in Chapter 2.

**Table M1: Guidelines to interpret parents' problem definition score**

Actual Score	Interpretation	Implication for relevant ECCI planning
4.00	Excellent problem definition skills	Information is very well organized, and extremely relevant. Therapist has an excellent understanding of the problem and needs. Relevant ECCI planning is facilitated to an extremely large extent.
3.5-3.9	Very good problem definition skills	Information is well organized, and very relevant. Therapist has a very good understanding of the problem and needs. Relevant ECCI planning is facilitated to a very large extent.
3.0-3.4	Good problem definition skills	Information is organized, and relevant. Therapist has a good understanding of the

Actual Score	Interpretation	Implication for relevant ECCI planning
		problem and needs. Relevant ECCI planning is facilitated to a large extent.
2.5-2.9	Moderately good problem definition skills	Information is somewhat well organized, and relevant. Therapist has a somewhat good understanding of the problem and needs. Relevant ECCI planning is facilitated to a somewhat large extent.
2.0-2.4	Moderately poor problem definition skills	Information is somewhat poorly organized, and of some relevance. Therapist has a somewhat poor understanding of the problem and needs. Relevant ECCI planning is facilitated to some extent.
1.5-1.9	Poor problem definition skills	Information is poorly organized, and of limited relevance. Therapist has a generally poor understanding of the problem and needs. Relevant ECCI planning is facilitated to a limited extent.
1.1-1.4	Very poor problem definition skills	Information is very poorly organized, and of very limited relevance. Therapist has a very poor understanding of the problem and needs. Relevant ECCI planning is facilitated to a very limited extent.
1.00	Extremely poor problem definition skills	Information is extremely poorly organized, and of very limited to no relevance. Therapist has an extremely poor to no understanding of the problem and needs. Relevant ECCI planning is facilitated to an extremely limited extent to not at all.

## Appendix N

### Development of the Biographical Information Questionnaire

Table N1 provides a detailed outline of the development of the Biographical Information Questionnaire.

Table N1

*Development of biographical information questionnaire*

Part in questionnaire	Category	Total # of questions	Question #	Question area	Type of question	Motivation
	<b>General interview information</b>	4	1	Parent identification number Referral source	Open-ended	Allocating a number to each parent/caregiver interviewed protected anonymity during the administration of the data collection and analysis procedures. A similar method was utilized by Chang (1996). The referral source (i.e. institution) was noted to coordinate data collection.
			2	Experimental or control group	Closed-ended	To facilitate data analysis for each group and interpretation of training outcomes.
			3	Date of Interview Pre-training or post-training	Closed-ended	Recording the date of the interview was important for 2 reasons: (a) to differentiate between the pre and post-training interviews and (b) to ensure that the time span between each interview for each participant was controlled, as per the requirements of the selected research design (McMillan & Schumacher, 2010)
			4	Participant's relationship to the child (mother, father, caregiver)	Closed-ended	Research indicates that fathers and mothers cope differently to parenting children with communication disabilities (Frey et al., 1989). The latter may therefore influence parents' orientations to and definitions of problems experienced – which may have implications for ECCI planning and programming.
1	<b>Biographical information on the parent/caregiver</b>	8	5	Contact Details (name, address)	Open-ended	Information required to facilitate the interview process, and to inform parents about arrangements regarding the two interviews and training programme (for those in the experimental group). This information was included in a separate sheet that could be detached from the questionnaire. The parent identification number was noted as well.

Part in questionnaire	Category	Total # of questions	Question #	Question area	Type of question	Motivation
			6	Age	Closed-ended Five options: <20 years 20-30 years 31-40 years 41-50 years >50 years	The latter was done to ensure the parents' anonymity during the data capture process. Parents' ages were determined to identify whether it influenced parents' orientations to and skills in problem definition, as older parents may have more experience in coping and adapting to their adverse circumstances in comparison with younger parents, and may therefore demonstrate more positive or negative orientations. Seltzer, Greenberg, Floyd, Pettee & Hong (2001) found that parents of children with developmental disabilities who were older and had more time to develop their adaptations, accommodations and resilience coped better than those who were younger and had less time.
			7	First language and Race	Closed-ended Eight options: - English-Indian/White/Black/Coloured -Other language-Indian/White/Black/Coloured	To determine whether parents were first language English speakers. The latter is likely to influence parent's skill in describing and defining their problems to health professionals (Cegala et al., 2000). In addition, the parents' first language and race group were used as indicators to gauge their cultural backgrounds. Parents' cultural backgrounds may influence their problem orientations (beliefs regarding disability, attributions about etiology and importance, treatment outcome expectancies etc) and their definition of problems (based on parent expectations). The literature indicates that the parent's cultural background plays an important role in shaping expectations and interpretations of disability, which in turn may influence parent participation in ECI (Harry, 2002; Chang, 1996; Zhang & Bennett, 2001).
			8	Highest level of education	Closed-ended six options: - did not attend school - primary school - high school	Parents' orientation to and definition of problems experienced require their use of cognitive and linguistic skills – both of which may be influenced by parents' level of education (D'Zurilla & Nezu, 1999). Education is associated with an individual's ability to develop social networks, which is an important source of support for parents of children with disabilities (Sloper, 1999). Parents who are better educated are also more likely to be employed in occupations that have

Part in questionnaire	Category	Total # of questions	Question #	Question area	Type of question	Motivation
2	<b>Biographical information on the family</b>		9	Employment	<ul style="list-style-type: none"> <li>- completed high school</li> <li>- tertiary education</li> <li>- post-graduate education.</li> </ul> Closed ended Three options: <ul style="list-style-type: none"> <li>- full-time</li> <li>- part-time</li> <li>- unemployed.</li> </ul>	<p>a higher income, thus increasing financial resources to cope. The latter may influence parents' orientation to problems experienced in parenting children with disabilities.</p> <p>The study focused on parents from low income backgrounds who accessed ECCI services at public health institutions. Parents' employment status influences their financial resources as well as time available for parenting. Limited financial resources and lack of time are identified as additional stressors confronting parents of children with disabilities (Singer &amp; Irvin, 1989; DSD, DWCPD &amp; UNICEF, 2012).</p>
			10	Marital Status	Closed ended four options: <ul style="list-style-type: none"> <li>- married</li> <li>- living with a partner</li> <li>- single</li> <li>- other</li> </ul>	Research findings indicate that two-parent families have better social support and tend to cope better than single-parent families – a factor that may influence parents' orientation to and definition of problems experienced in parenting children with disabilities (DSD, DWCPD & UNICEF, 2012). Marital satisfaction was also found to be the best overall predictor of the coping behaviour of mothers with children with disabilities (Taanila et al., 2002).
			11	Physical and mental health	Closed-ended four options: <ul style="list-style-type: none"> <li>-excellent</li> <li>- good</li> <li>- not so good</li> <li>- poor</li> </ul>	Parents' mental and physical health are important coping resources (Folkman et al., 1979) which may affect parent's orientation to and definition of problems, Poor physical and mental health (particularly depression) have been found in some parents of children with disabilities, especially from low-income/under resourced backgrounds (Singer & Irvin, 1989; DSD, DWCPD & UNICEF, 2012).
			12			
		13	Total family income per month	Closed-ended seven options: <ul style="list-style-type: none"> <li>&lt;R500</li> <li>R501-R1000</li> <li>R1001-R1500</li> <li>R15001-R2000</li> </ul>	According to the absolute poverty line utilized in a summary report for the South African Department of Social Development, the minimum income necessary to keep a household out of poverty is an average of R311 per person (Economic Policy Research Institute, 2004). This figure was used to calculate the family's income in relation to the poverty line.	

Part in questionnaire	Category	Total # of questions	Question #	Question area	Type of question	Motivation
3	<b>Biographical Information on the Child</b>	3	14	Name	Open-ended	The child's name was obtained and used during the interview in order to personalize the questions posed to the parent/caregiver, thereby facilitating rapport and parents' willingness to participate in the interview. The name was recorded on the separate sheet, together with the parent's contact details, in order to ensure confidentiality and anonymity of information.
			15	Age	Closed-ended Three options: 0-2yrs 2.1-4yrs 4.1-6yrs	Children's ages were recorded to ensure that they were in the age range 0-6 years in order to benefit from ECI services (Shonkoff & Meisels, 2000). Children in this age range receive free health care services at public hospitals and assessment and therapy centers in South Africa (Office of the Deputy President, 1997; NPC, 2011), thus enabling the researcher access to parents from adverse socioeconomic backgrounds.
			16	Primary Medical Diagnosis (Established Risk Factor)	Closed –ended Nine options - chromosomal disorders - neurological disorders - sensory disorders - congenital malformations - inborn errors of metabolism - atypical development - severe toxic exposure	The primary medical diagnosis as recorded in the hospital/clinic medical records was used to identify children presenting with communication disabilities <i>secondary</i> to a diagnosed medical condition (e.g. Down syndrome, hearing impairment, mental retardation, and other conditions referred to in Rossetti, 2001). The latter represent established risk factors, as adverse effects on the children's developmental outcome are known and expected (Rossetti, 2001). In order to facilitate effective ECCI planning, parents' definition of problems experienced must be specific to the child's communication and/or oral motor disabilities and the effect it has on the family's daily life routine and functioning. Gallimore et al. (1989) & Alant (2005b) indicate that families actively create family routines that will accommodate the child with a disability. When defining problems to the professional, descriptions should be relevant to the family's routine and functioning, and parents must describe the

Part in questionnaire	Category	Total # of questions	Question #	Question area	Type of question	Motivation
					- chronic medical illness - severe infectious disease	specific difficulties that they experience in accomplishing the latter, so that ECCI goals, approaches and methods are selected to address these difficulties, by either modifying the child's communication response and/or the communication environment. The latter would ensure effective and sustainable treatment, which in turn will sustain parents' active participation during intervention. Alternatively, if the parent's definition focuses primarily on the unalterable established risk factor as opposed to the alterable developmental problem of functional communication, then parent/ family focused (in combination with child focused) intervention planning is required (Dunst, 2004; Neely-Barnes & Dia, 2008). For example, parent education and counseling utilizing strategies such as information sharing and redefinition (Sameroff & Fiese, 2000). Thus, parent's orientations as well as skills in problem definition will strongly influence the programming of ECCI goals, approaches and methods.
4	<b>Speech-language therapy summary profile:</b>  Child's communication disability	5	17	Speech-language therapist's assessment of the child's communication disability: <i>Developmental domains:</i> • Cognitive skills • Motor skills • Communication skills - Receptive language - Expressive language	Closed ended four-point scale: 1- poor 2- average 3- good 4- very good	Findings with respect to the child's cognitive, motor, communication and social/pragmatic skills (specifically, the nature and severity of the communication disability), were ascertained in order to obtain a fairly comprehensive understanding of the child's developmental skills, as well as ascertain the reliability of parents responses. Rossetti (2001) identifies these as important areas of assessment in ECI. However, discussions with therapists revealed that the assessment tools used at the three speech-language therapy service sites differed greatly with respect to formal and informal methods. Thus, in order to ensure consistency of information regarding the child's performance in each developmental domain, speech-language therapists were asked to rate the child's ability on a four-point scale – based on their respective assessments.

Part in questionnaire	Category	Total # of questions	Question #	Question area	Type of question	Motivation
				<ul style="list-style-type: none"> <li>Social/Pragmatic skills</li> </ul>		
			18	Speech-language therapist's estimate of severity of the child's communication disability	Closed-ended Three options: - moderate - moderate to severe - severe	<p>Children with moderate to severe communication disabilities were selected as they present significant challenges to parents (Rossetti, 2001; NCP, 2011). The speech-language therapist's estimate of the severity of the communication disability was based on a composite of information from the developmental domains listed. The classification system utilized by Cho et al., (2000, p. 239) to determine severity of disability was adapted to include receptive language skills together with the existing indicators of expressive language skills and basic self-help skills. In addition, the category of moderate to severe was added to cater for children in this category. Thus severity was rated as follows:</p> <p><b>Moderate disability:</b> basic expressive and basic or higher receptive communication skills, including basic pragmatic functions, needs less assistance with basic self-help skills but still requires prompting.</p> <p><b>Moderate to severe disability:</b> some basic expressive and basic receptive communication skills, including some basic pragmatic functions. Needs less assistance with basic self-help skills but still requires much prompting.</p> <p><b>Severe disability:</b> little or no functional communication skills, learning basic self-help skills but requires significant assistance. .</p>
Parent/ Caregiver's health and coping			19 20	Informal assessment of parent's physical and mental health	Closed ended three-point scale - good - satisfactory	<p>Parenting children with moderate to severe disabilities can have a significant effect on parents' physical and mental health, which can influence parents' orientation to and definition of problems experienced (Singer &amp; Irvin, 1989; Saloojee et al., 2007).</p>

Part in questionnaire	Category	Total # of questions	Question #	Question area	Type of question	Motivation
			21	Informal assessment of parental coping	- poor Closed ended five-point scale: 1-positive 2-somewhat positive 3-somewhat negative 4-negative 5-not assessed	Research indicates that some parents may experience difficulties in coping and adapting to parenting a child with a disability, particularly in under-resourced contexts (Singer & Irvin, 1989; Saloojee et al., 2007; NPC, 2011). The latter may influence parents' orientation to children's communication problems. Parent support programmes are therefore strongly recommended as part of ECI services (Rossetti, 2001; Dunst et al., 1988, 1994a). Alternatively, the question provided a method of establishing the reliability of the parent's responses on the Problem Orientation Questionnaire.

## Appendix O

### Biographical Information Questionnaire

		<b>Parent Number:</b>	<b>V1</b>	
<b>Institution:</b>		<b>Date:</b>		
		1 Experimental Group	<b>V2</b>	
		2 Control Group		
		1 Pre-training Interview	<b>V3</b>	
		2 Post-training Interview		
<b>1. Participant's relationship to the child:</b>			<b>V4</b>	
1	Mother			
2	Father			
3	Caregiver			
<b>Part 1: Biographical Information: Parent/Caregiver</b>				
<b>2. Contact Details (refer to attached sheet)</b>				
<b>3. Age:</b>			<b>V5</b>	
1	<20 years			
2	20-30 years			
3	31-40 years			
4	41-50 years			
5	>51 years			
<b>4. First/Home Language and Race :</b>			<b>V6</b>	
1 English-Indian	3 English-White	5 English-Black	7 English-Coloured	
2 Other Language- Indian	4 Other Language- White	6 Other Language- / Black	8 Other Language- Coloured	
<b>5. Highest level of education:</b>			<b>V7</b>	
1	Did not attend school			
2	Completed primary school			
3	Did not complete high school			
4	Completed high school			
5	Tertiary education			
6	Post-graduate education			
<b>6. Marital Status</b>			<b>V8</b>	
1 Married	2 Single	3 Living with partner	4 Other	
<b>7. Employed</b>			<b>V9</b>	
	1 Yes	2 No		

<b>Specify occupation/ employment</b>					
<b>8. Physical Health</b>					
1 Excellent	2 Good	3 Not so good	4 Poor	<b>V10</b>	
<b>9. Mental Health</b>					
1 Excellent	2 Good	3 Not so good	4 Poor	<b>V11</b>	
<b>Part 2: Background Information on the Family</b>					
<b>10. Total family income per month</b>				<b>V12</b>	
1	<R500				
2	R501-R1000				
3	R1001-R1500				
4	R1501-R2000				
5	R2001-R3000				
6	R3001-R4000				
7	>R4001				
<b>Part 3: Background Information on the Child</b>					
<b>11. Age:</b>		<b>Date of Birth:</b>			
1	0-2yrs	2	2,1-4yrs	3	4,1-6yrs
<b>12. Primary Medical Diagnosis (Established Risk Factor)</b>				<b>V13</b>	
1	Chromosomal Anomalies/Genetic Disorders <i>e.g. Down Syndrome</i>			<b>V14</b>	
2	Neurological Disorders <i>e.g. Cerebral Palsy, Seizure Disorders, Head and Spinal Cord injuries</i>			<b>V15</b>	
3	Congenital Malformations <i>e.g. Cleft Palate, Spina Bifida, Microcephaly</i>			<b>V16</b>	
4	Inborn Errors in Metabolism <i>e.g. Hunter Syndrome, Tay-Sachs Disease</i>			<b>V17</b>	
5	Sensory Disorders <i>e.g. Hearing Loss, Visual Impairment/Blindness, Retinopathy of prematurity</i>			<b>V18</b>	
6	Atypical Developmental Disorder <i>e.g. Autism, Failure to Thrive (non-organic)</i>			<b>V19</b>	
7	Severe Toxic Exposure <i>e.g. Fetal Alcohol Syndrome, Cocaine and other drugs</i>			<b>V20</b>	
8	Chronic Medical Illness <i>e.g. Cancer, Medically Fragile, Cystic Fibrosis</i>			<b>V21</b>	
9	Severe Infectious Disease <i>e.g. Poliomyelitis, Viral and Bacterial Meningitis, Rubella, Herpes, Encephalitis, Syphilis, HIV+</i>			<b>V22</b>	
<b>Part 4: Speech-Language Therapy: Summary Profile</b>					
<b>14. Rating of general developmental skills</b>					
1 age inappropriate	2 age appropriate	3 above age level			
Cognitive skills				<b>V23</b>	
Motor Skills				<b>V24</b>	

Receptive Language				V25	
Expressive Language				V26	
Pragmatic/Social Skills				V27	
<b>15. Severity of Communication Disability</b>				V28	
1 moderate	2 moderate to severe	3 severe			
<b>16. Informal assessment of parent's general health (physical and mental )</b>					
Physical health	1 poor	2 satisfactory	3 good	V29	
Mental health	1 poor	2 satisfactory	3 good	V30	
<b>17. Informal assessment of parental coping</b>					
<i>(implementing child's daily care-giving and intervention activities; meeting demands of work and/or other family members; caring for self, etc.)</i>					
1 Not coping at all (negative)	2 Coping with very few demands (somewhat negative)	3 Coping with a fair number of demands (somewhat positive)	4 Coping with most or all demands (positive)	5 Area not assessed	V31

## Appendix P

### Measuring instruments and consistency expected in parents' responses between pre- and post-training evaluations

*Measuring instruments and consistency expected in parents' responses between pre- and post-training training evaluations*

<b>Measuring Instrument</b>	<b>Question responses expected to remain consistent in the pre-and-post training evaluations</b>	<b>Question responses not expected to remain consistent in the pre-and-post training evaluations</b>
1. Biographical Information Questionnaire	<p><i>The majority of variables are expected to remain consistent in the experimental and control groups:</i></p> <ul style="list-style-type: none"> <li>• General information: V1-2, V4</li> <li>• Biographical information on Parent: V5-9</li> <li>• Biographical information on family: V12-17</li> <li>• Biographical information on child: V14-22</li> <li>• Speech-language therapy summary profile: V23-31</li> </ul> <p><i>Changes are possible in the following, but are quite unlikely.</i></p> <ul style="list-style-type: none"> <li>- V12 (total income of the family)</li> <li>- V13 (child's age – if the child enters a higher category)</li> <li>- V23-27 (the child's general development in the areas of cognition, motor skills, receptive and expressive language, pragmatic/social skills. However, dramatic changes are very unlikely considering the nature of the disability and the relatively short time-span between measures)</li> </ul>	<p><i>The following five questions may present with variable scores due to the effects of training for the experimental group:</i></p> <ul style="list-style-type: none"> <li>• General Information: V3 (pre-or-post training interview)</li> <li>• Background information on parent: V10 &amp; 11( parent's physical and mental health)</li> <li>• Speech-language therapy summary profile:               <ul style="list-style-type: none"> <li>- V29-V30 (speech-language therapist's informal observation of parent's physical and mental health)</li> <li>- V31 (speech-language therapist's information observation of parental coping)</li> </ul> </li> </ul>
2. Problem Orientation Questionnaire	<p>Variables are expected to remain consistent for experimental and control groups if parents' orientations were positive at pre-training.</p>	<p>Variables are expected to change if pre-training scores did not reflect positive orientations, especially for experimental group.</p> <ul style="list-style-type: none"> <li>• Problem perception: V32-34</li> <li>• Problem attribution: V35-38</li> <li>• Problem appraisal: V39</li> <li>• Personal control:               <ul style="list-style-type: none"> <li>- V40 (outcome expectancy )</li> <li>-V41-43 (self efficacy)</li> </ul> </li> <li>• Time and effort : V44-46</li> </ul>
3. Problem Definition Question	<p>None of the variables are expected to remain consistent in the experimental group.</p>	<p>Changes between pre-and-post training scores are expected in all variables for the experimental group: V47-52,</p>

## Appendix Q

### Description of the training philosophy and methods used to facilitate parents' positive problem orientations and problem definition skills

#### (i) Training philosophy

Parent capacity building using family-centered intervention practices (Dunst, 2004) was the overall philosophy that guided the development and implementation of the POD training programme. The main training principles centered on building the capacity of parents in seeking help from ECCI. Table Q1 briefly discusses the training philosophy and principles utilized in the study, based on a review of literature that was relevant for parent training in ECCI.

Table Q1

*Training philosophy and principles used to facilitate parents' positive problem orientations and problem definition skills*

Training philosophy and principles	Brief description and application in the study
<p><b>Overall training philosophy:</b>            Parent support through capacity building using family-centered help-giving practices.            The following five principles guided training at all levels:</p> <ul style="list-style-type: none"> <li>- promotion</li> <li>- empowerment</li> <li>- strengths-based</li> <li>- resource-based</li> <li>- family-centered</li> </ul>	<p>Early childhood intervention and family support is defined as “the provision of support and resources to families of young children from informal and formal social network members that both directly and indirectly influence child, parent, and family functioning.” (Dunst, 2004, p. 2). The emphasis on <i>parent and family support</i> and capacity building as the <i>principle means</i> of strengthening the child’s functioning (Dunst, 2004), is particularly relevant for this study. The framework draws from social systems and ecological theory in viewing the child, parent and family’s learning and development as a function of person and environment factors, <i>and</i> the combined complex transactional influences and interactions of both factors (Dunst, 2004, Sameroff &amp; Fiese, 2000). The significance of environmental factors in influencing the child’s learning and development is emphasized in the ECI literature, particularly the social environment that includes the parent and family (Dunst, 2004; Rossetti, 2001; Sameroff &amp; Fiese, 2000). Parents’ help-seeking skills are located in the child’s social environment.</p>
<p><b>Training structure:</b>  <b>Change management:</b></p>	<p>Conceptually, the integrated model is underpinned by <i>five principles</i> representing a shift from the traditional professionally driven, problem focused, and deficit-based paradigm toward a <i>capacity-building paradigm</i> (Dunst, 2004). The paradigm is pivotal in recognizing the potential of parents’ help-seeking skills in enhancing the child and family’s positive functioning, and in identifying core elements of parent support in this regard. As applied to developing parent support in this study, the five principles are: (i) <i>promotion</i> (i.e. optimizing parents’ competence and positive functioning in parenting young children with disabilities), (ii) <i>empowerment</i> (i.e. creating opportunities for parents’ to illustrate existing capabilities and develop new competencies), (iii) <i>strengths-based</i> (i.e. recognizing parents’ individual and environmental assets and using these to strengthen positive functioning in the child and family), (iv) <i>resource-based</i> (i.e. utilizing a range of family and community opportunities and experiences to optimize functioning), and (v) <i>family-centered</i> (i.e. placing the family and their concerns and needs central in the help-giving process) (Dunst, 2004; Dunst et al., 1994a; Neely-Barnes &amp; Dia, 2008).</p>

- social cognitive theory  
(Bandura, 1998; 2001)

In providing a broad biopsychosocial understanding of human development, adaptation and change, the theory outlined the central mechanism to facilitate parents' help seeking during ECCI. The key principle that guided the teaching and learning process was that parents were important change agents and that their endowments (i.e. age, physical and mental health), belief systems, self-regulatory capabilities and social structures (socioeconomic, educational, cultural & family) influenced their functioning as help seekers. Three critical mechanisms for influencing positive problem orientation and definition were involved. First at a *personal agency level*, their intentions (i.e. proactive commitment to adopt positive POD skills), perceived self-efficacy (i.e. believe that they are capable of learning and benefiting from the training) and outcome expectancies (i.e. believe that training will enhance their POD knowledge, attitudes and skills, and thereby help seeking competence). Second at a *proxy agency level* (i.e. other people who could assist them to achieve their desired outcomes), health care professionals, like the SLT would support them in their roles as help seekers, to access the help that they needed (i.e. knowledge and skills) to parent their child effectively. Third, at a *macro, collective level*, by being part of a bigger group of parents with similar goals they could support each other toward goal achievement. Thus, training played particular attention in providing the appropriate knowledge, values and skills that supported parents' positive intentions and beliefs about perceived self-efficacy and outcome expectancies during problem orientation and definition in ECCI (already outlined in Table 1).

- factors mediating change process (Crookes, 1998)  
- Health action process approach (HAPA) (Schwarzer, 1999)

Training in POD focused on facilitating positive changes to parents' problem orientations and definition skills so that they were able to access the help that they needed from ECCI professionals. The current literature on health behaviour change emphasizes the need for a systematic approach to change management, to optimize and sustain positive intervention outcomes (Crookes, 1998; Schwarzer, 1999). The four phases of the Health Action Process Approach (HAPA) (Schwarzer, 1999) provided the broad framework for change management, and the five critical factors proposed by Crookes (1998) were included. While the essential attributes of both frameworks are recognized in healthcare intervention literature (Crookes, 1998; Schwarzer, 1999; Schwarzer & Renner, 2000), the parent intervention literature reviewed in Table 2 and Table 3 reflect the need for greater management of the change process. The four phases included motivation and goal setting, initiating and maintaining perceptual and behaviour changes, and evaluating the design, implementation and outcome of training (Schwarzer, 1999). The five factors that mediated positive training outcomes (Crookes, 1998) included: attributes of parents and their social, economic, educational and linguistic environments (discussed in Section 2.4.1.1); attributes of the theoretical framework of problem orientation and definition underpinning training (proposed in Table 1); competence of the trainer (discussed later in Section 3.4.2.4.1); and the training philosophy and methods selected to initiate and sustain the change process. Appendix U illustrates the application of the frameworks in more detail.

- parents' adaptation process (Barnett et al., 2003)

Parents healthy adaptation to children's disabilities is crucial to optimize sensitive parenting, and thereby enable parents to provide specific, concrete, and comprehensive descriptions of problems experienced. Barnett et al. (2003) outlined a mechanism to facilitate parents' positive adaptation to parenting children with disabilities, namely; social, emotional, cognitive and behavioural. POD training ensured that the four processes were included in the training plan. Social processes included group interactions so parents shared challenges with other parents facing similar situations. Emotional processes were addressed by providing opportunities for parents to express their emotions (negative/positive) and finding healthy ways of managing negative emotions. Cognitive processes enabled parents to increase their knowledge about child development; parent attributions regarding cause of disability, etc. Finally, behavioural processes

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promoted parenting skills specifically in communicating their problems and needs to SLTs. .

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**Training process:**

(i) Parent-professional partnership

- value-based partnership with oppressed groups (Nelson et al., 2001)

The relationship/partnership between parents and trainer was a critical factor facilitating positive changes in parents' problem orientations and definitions (Nelson et al., 2001). Relationship building was based on the following core values that guided how the trainer thought and acted during the study: caring, compassion and community (i.e. making parents' feel safe, accepted and comfortable in order to foster trust); mental and physical health (i.e. ensuring that parents' understood the significance of being competent in help seeking to promote healthy functioning of the family); participation, self-determination and power sharing (i.e. parents having a voice and choice in all aspects of training); human diversity (i.e. respect parents' unique identities without judgements); social justice (i.e. fair and equitable distribution of resources amongst participants during training). Parents and trainer developed a collective vision of the aim and outcomes of training from the outset. Guidelines were followed for developing trust (e.g. open communication, active listening); resolving conflict (e.g. role clarification, mutual understanding of expectations); establishing ground rules and procedures to guide behaviour of partners during training (e.g. training times, communication amongst participants, etc.); power-sharing (i.e. active participation of parents, voice feelings and opinions), managing challenges of participants' diversity in terms of race, abilities, culture, etc.

- Empowerment activation and process (Finfgeld, 2004; Cortes et al., 2009)

The empowerment process was carefully planned over the four phases of training to enable parents to recognize their "personal strengths, meanings and purposes" so that they felt that they had greater control when seeking help during ECCI (Finfgeld, 2004, p. 44). Finfgeld's model of empowerment was followed as it described the process of empowerment in terms of antecedents, barriers, attributes and outcomes. Although the model was developed for use with individuals with enduring mental health problems, it was also relevant for parents of children with established disabilities and associated communication disabilities for reasons already discussed in Section 2.3.1.1. Parents' loss of power through stigmatization and oppressive health systems, willingness to assume personal responsibility, self confidence, self-efficacy, cognitive skills (i.e. intrapersonal issues), and parent-professional power sharing and professionals' use of empowerment enhancing communication during training (i.e. interpersonal issues), were important factors that promoted empowerment. Important barriers for parent empowerment included stigma (e.g. beliefs about disability), parents' lack of motivation, impaired cognitive abilities, institution's organization and structure and staff resistance. The model identified four core processes of empowerment that reflected gradual progress in the empowerment process, namely, participating, choosing, supporting and negotiating. Parents' progress through the empowerment process was tracked in terms of parents' use of these behaviours. Outcomes could be positive (e.g. parents' engaging actively in the training process, feeling that they have a voice and choice in the process) or negative (e.g. feeling inadequate, frustrated, distressed, no opportunity to voice opinions). The model provided a systematic framework to describe and support parents' empowerment over the four-day training process.

Family-centered help-giving (Dunst, et al., 2002)

Training focused on parent identified needs and solutions regarding problem orientation and definitions. Both relational and participatory help giving practices were used to facilitate parents' competence in approaching and accessing help during ECCI. Relational help giving behaviours (i.e. empathy, warmth, genuineness, beliefs about parents' help-seeking capacities.) were important to promote parents' positive functioning by recognizing and acknowledging their

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strengths, and personal and family assets that were relevant for problem orientation and definition. Participatory help giving behaviours (i.e. actively involving parents in identifying desired goals and in decision making about actions to achieve it, giving parents' choices, promoting collaboration between parent and trainer) were important ways in which parents were empowered to use positive problem orientations and definitions during training. Dunst et al. (2002) emphasized that while relational help giving behaviours occurred in all family orientated models, it was participatory help giving behaviours that were critical in ensuring family-centered programmes.

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**(ii) Teaching and learning process**

- authentic curriculum-based approach (Bagnato et al., 1997, Bagnato, 2010; Bricker & Cripe, 1992);

Parents' competencies in the role of help seeker in ECCI were identified, specifically consumer and decision maker (Granlund et al., 2005). Underlying values, beliefs and skills were derived from the dimensions of problem orientation and definition in social problem-solving theory (D'Zurilla, 1986; D'Zurilla & Nezu, 1999). Aspects critical to facilitate parents' approach to ECCI professionals for help, and communication of their problems and needs, were identified. A framework of problem orientation and definition was thus proposed as a basis to guide training in the two variables (Table 1 in Section 2.3). The framework was authentic as it was derived from parent identified problems and needs during help seeking in ECCI, through a focus group discussion with parents and speech-language therapists (see Table 4, Section 3.4.1.1.1).

- Participatory Adults Learning Strategy (PALS) (Dunst & Trivette, 2009)

PALS provided an evidence-based approach to parent training that describes the characteristics of teaching and learning methods and the conditions that promote adult learning. Trainer and trainee roles are included as well, emphasizing the bidirectional context of learning between trainer and parent. POD training used the six adult learning methods (i.e. introduce, illustrate/demonstrate, practice, evaluate, reflection and mastery) as recommended under the three conditions of planning, application and deep understanding. These were included within the four phases of training and is detailed in Appendix U). Research found that the inclusion of greater number of learning methods increased the training effect size (Dunst & Trivette, 2009). Key principles that informed training included active parent participation during learning (using, processing and evaluating knowledge and skills); introducing information incrementally to build on parents existing knowledge and skills (parents don't need to understand everything about the knowledge or skill to use it); learner engagement in judging own and others performance; increased learning opportunities over the four training days; and use of trainer guided learning opportunities.

- constructive, experiential learning (Sawyer, 2006; Kolb & Kolb, 2005)

In addition to the PALS framework described, broader teaching and learning approaches were also used. A constructivist approach acknowledged that parents entered the training programme with an existing knowledge, attitude and skills base that was derived from previous formal and informal learning experiences. Training therefore commenced at the level that parents were (derived from the pre-training assessment), and supported parents in transforming to new ways of thinking and communicating (acting) during problem orientation and definition in ECCI. Training included an experiential component where parents engaged in simulations/ role play activities so that they could situate their learning in their own help seeking activities.

Additional principles included parents *articulating their developing understanding* through sense-making conversations guided by the trainer; viewing *learning as both individual and social*, and the social interaction process triggers and supports the learning process. Teaching strategies were directed to parents individually (e.g. journal writing) and in a group context (sharing parent stories; role-playing; supporting and contributing to each others learning, asking questions). Developing parents' capacity for *reflection* to help them become aware of underlying assumptions (e.g. cause of disability), perceptions of constraints &

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enablers for positive functioning, etc. Reflection tasks promoted deep learning and understanding of concepts (e.g. self-efficacy, problem definition). Finally, using visual methods (e.g. power-point slides, videos) to make abstract information concrete (e.g. how to define problems and needs)

## (ii) Training methods

Training methods were selected to facilitate positive changes in parents' cognitions, emotions and behaviours related to parents' orientation to and definition of problems experienced in parenting young children with moderate to severe communication disabilities, secondary to established disabilities (D'Zurilla & Nezu, 1999; Barnett et al., 2003). The methods also promoted parents' active participation in learning to enhance capacity-building outcomes (Dunst & Trivette, 2009; Dunst et al., 2002). Table Q2 briefly discusses the training methods and application in the study.

**Table Q2: Training methods used to facilitate parents' positive problem orientations and problem definition skills**

Training methods	Brief description of use during training
<b>Facilitation strategies</b>	
Image-making	Parents needed to construct a positive new image of themselves as parents of children with disabilities, to cope positively (Scorgie et al., 1996, 1999; Scorgie & Sobsey, 2000). The concept of "mother warrior" or "warrior mum" as used in this study, was introduced by actress Jenny McCarthy when she appeared on "The Oprah Winfrey Show", which aired on television on 10 September, 2010. Her son was diagnosed with autism, and she became an advocate for parents of children with the disorder. She discussed her book entitled "Mother Warrior", and indicated that the concept referred to mothers fighting for the rights of children born with special needs. In this study, the term captures the critical roles of parents as decision-maker, consumer, change agent, advocate, etc. in parenting children with disabilities. The concept is presented in the story of the mum who had her limbs amputated after the birth of her baby (discussed later). The image is easy for parents from different cultural backgrounds to relate to, and to use to understand their role.
Sharing personal stories/experiences of parenting children with disabilities	The process of sharing individual experiences enabled parents to recognize similarities and differences between their own experiences and those of others, thereby facilitating rapport building between participants (Finfgeld, 2004; Niederhoffer & Pennebaker, 2002; Woods & Lindeman, 2008). The process also allowed parents to express their positive and negative emotions in a supportive environment, and to have these emotions acknowledged (i.e. parent "voice" is heard) (Nelson et al., 2001).
Cognitive reframing/ restructuring, positive reframing; perspective changing	Facilitates changes in thinking about events by "correcting irrational beliefs, exaggerated threat appraisals, unrealistic goals, and other cognitive distortions." (D'Zurilla & Nezu, 1999, p. 118). The trainer provided relevant information from ECI literature to trigger changes in parents' thinking about disability (e.g. causes, outcomes, self efficacy, etc.) and the collaborative partnership between parents and professionals (e.g. equal partnership, active involvement). It promotes meaning-making and perspective changes, for example, by comparing themselves to other parents or individuals who confront problems that are more severe (Taylor, 1983). Appendix A indicates that it is used widely in parents who were coping positively.
Lectures	Effective strategy for providing new information to facilitate learning (Dunst & Trivette, 2009). Used to provide information about key principles that promote effective problem orientations (i.e. perception, causal attribution, personal control, appraisal and commitment of time and effort), and problem

	definition (presenting relevant information in an organized three-step format).
Guided reflection, modeling	Learners' reflection on the learning experience promotes deep understanding of the learning topic and is associated with positive behaviour changes (Dunst & Trivette, 2009). In view of the parents' diverse educational backgrounds, the trainer guided parents through the reflection process, using critical questions. For example, after watching the video "are you going to finish strong", the trainer modeled the reflection process by asking questions to help parents identify strategies that the person used to cope positively with a difficult situation. The process of reflection enabled parents to recognize relevant strategies that they could use, and also established that the strategies do work for other people in similar or different contexts.
Role-play, practice	These are important components of communication skills training (Cegala et al., 2000), as learners are able to apply information given in lectures, and practice within a controlled environment (Dunst & Trivette, 2009; D'Zurilla & Nezu, 1999, 2010). For example, parents used role-play to practice communicating their problems and needs to speech-language therapists when accessing intervention.
Constructive feedback, evaluation	Enabled learners to evaluate the consequences of applying the learning topic (Dunst & Trivette, 2009). According to Cegala et al. (2000), face-to-face training intervention allows the trainer to tailor instruction specifically to patient needs. Trainer feedback and peer feedback were used to enable parents to evaluate their learning. For example, parents received trainer feedback and peer feedback when practicing problem definition skills and they were encouraged to use this feedback to improve problem definition skills.
Learner input, group problem-solving discussions	Learners' knowledge and experience were used to problem solve and construct guidelines for parents to use in two contexts that were identified as areas of concern during pre-training: (i) managing cultural attributions for the cause of disability that were not supportive of the parent (especially when the mother is blamed), and (ii) being confident and expressing your love when introducing the child with disability to other people.
<b>Illustrations of positive functioning using motivational power-point slideshows</b>	Downloaded from the internet, using Google search, and key words "inspirational slideshows". The messages are inspirational and motivate individuals to adopt positive perceptions and outlooks to cope with stressful experiences.
"We are like pencils" <a href="http://www.slideshare.net/kath1201/we-are-like-pencils-3736229">http://www.slideshare.net/kath1201/we-are-like-pencils-3736229</a>	An inspirational slideshow using the pencil as a simile to live one's life. Five important points are emphasized: (i) you can accomplish great things if you allow yourself to be guided by someone; (ii) you will experience a painful sharpening from time to time, by going through various problems, but you'll need it to become a stronger person; (iii) you will be able to correct mistakes you might make or grow through them; (iv) the most important part of you will always be what's on the inside; (v) on every surface you walk, you must leave your mark, and no matter what the situation, you must continue to have faith. Everyone is like a pencil, created by the Maker for a unique and special purpose. We must understand our situations from this context.
"Absolutely fantastic slideshow" <a href="http://www.slideshare.net/claeskrantz/absolutely-fantastic-slideshow-presentation-879444">http://www.slideshare.net/claeskrantz/absolutely-fantastic-slideshow-presentation-879444</a>	An inspirational slideshow that highlights important principles to live life meaningfully and happily. Some of the principles include: seeking friendships and support ; focusing on what we have rather than what we missed; enjoying our current experiences no matter what it is; accepting your situation and making the best of it; everything that happens to you, happens for a reason; the best things generally need the least effort; the greatest events are usually quiet experiences; and life is "drawing without an eraser".

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### Illustration DVD/Videos

“Are you going to finish strong?”  
 Video of a young man born without arms and legs.  
 - Modeling positive coping strategies in a different context.  
<https://www.youtube.com/watch?v=zOzsJEmjjHs>

Nick Vujcic was born without arms or legs but has come to terms with his life and disability. He presents an inspirational speech to high school children, emphasizing the need to persevere in reaching your goals, no matter how bad the situation may seem; and the benefits of having a sense of humour so that life is not taken too seriously. He helps children to see that there are better days ahead despite adversities that may befall them from time to time in life. The video provided a context for parents to compare their situations with others who confront problems that may be far more challenging, thereby facilitating positive coping (Taylor, 1983).

Video of a confident parent sharing her positive experiences of ECCI and the benefits that her child with severe communication disabilities secondary to cerebral palsy, derived from intervention. The parents’ decision to take an active role during intervention and its benefits for the parent and family, are also emphasized.

A confident, assertive parent in an ECCI program me at a local public hospital was selected. The child presented with severe communication disabilities secondary to cerebral palsy and was in the programme for two years. The aim of the video was to demonstrate what “positive coping and functioning” looks like with respect to parent’s personal control and active participation (i.e. positive outcome expectations, high self-efficacy, and positive perception of ECCI), and to also illustrate the benefits that parents experienced from intervention, for the child, parent and family (e.g. learning to make accommodations to the family’s daily routines and activities to facilitate family functioning, etc.). Parents could identify with the mother as she was from the local context, with a similar cultural, linguistic, education, and economic background as the majority of the mothers in the study. Appendix T briefly describes the development of the video.

- Real-life example of parent demonstrating characteristics of a “warrior mum” in the local ECCI context.

Simulations of parents using good and poor problem orientation and definition skills when seeking help from the speech-language therapist during ECCI.

Role-playing/simulations are effective training strategies to demonstrate good and poor communication of problems and needs during ECCI (Dunst & Trivette, 2009; Cegala et al., 2000; D’Zurilla & Nezu, 1999). The development of the videos are described in Appendix T. The parent simulation depicting good problem orientation and definition followed the guidelines described in the handout to access effective and sustainable intervention (i.e. “Getting the help you need when talking to professionals. A simple 2-step plan. – see Appendix S), whilst the parent simulation depicting poor orientation and definition did not. The videos provided a context for parents to actively engage in the learning process through observation, application of the guidelines from the handout, and evaluation.

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### Presentations incorporating real life experiences (Dunst & Trivette, 2009)

“Sharing my story as a cancer survivor”  
 - Real-life example of positive coping and functioning in a life-threatening context

Cancer is commonly perceived as a serious, life threatening illness, and the diagnosis is a challenge for many patients to cope with (Taylor, 1983; D’Zurilla & Nezu, 1999). Parent exposure to a patient who made a conscious decision to function positively in this context, enabled them to consider their problems in the context of other serious challenges that other people faced, to accept the situation and to move forward as the diagnosis will not change. The patient’s story was real, and she demonstrated positive functioning with respect to *problem perception* (recognizing symptoms, accessing medical care; accepting diagnosis and believing that medical treatment will help her); *causal attribution* (not blaming herself or any other factor but focusing on treatment); *personal control* (believing that she has the capacity to manage the treatment, that is, surgery, chemotherapy and radiation, and believing that she will feel better after the treatments); *appraisal* (viewing the illness as a challenge that she could manage), and

	<p><i>time and effort</i> (making changes to her life's daily activities and routines to incorporate the illness and treatments needed, taking all treatments as recommended etc.). She also demonstrated to parents how they could derive personal growth and benefits by taking their difficult challenges and the lessons that they learnt, and use it to support other parents facing similar situation, as she did in talking to them.</p>
<p>“Introducing my baby to other people”          - Individual presentation requiring parent’s application of learned material to introduce their child to the group</p>	<p>Appendix A shows that parents who function positively in parenting children with disabilities, treat the child like any other member of the family (Maul &amp; Singer, 2009; Turnbull et al., 1993). Parents were therefore encouraged to place greater emphasis on issues such as the child’s personality, strengths and hobbies, as they would when they introduced any other child in the family to others. They were told to include a brief description of the disability and the restrictions it imposed on the child, for example, communication, motor, cognitive functioning etc. (Turnbull et al., 1993; Maul &amp; Singer, 2009). Parents’ communication needed to reflect their positive appraisal of disability, and personal control (i.e. positive self-efficacy and outcome expectancy).</p>
Homework assignments	Facilitate practice and reflection of new knowledge, values and skills (D’Zurilla & Nezu, 1999; Dunst & Trivette, 2009).
<p>Case study – story of          “Meet a mother warrior”  <a href="http://www.oprah.com/slideshow/olahshow/20080910_tows_monica">http://www.oprah.com/slideshow/olahshow/20080910_tows_monica</a></p>	<p>Case studies facilitated learning as it illustrated the use of new knowledge, values and skills in the real context (Dunst &amp; Trivette, 2009). This story was shown on “The Oprah Winfrey Show” on television on 10 September 2008, and was downloaded from the show’s website on 5 May 2009. The story is about Monica, a mother of two daughters, who contracted necrotizing fasciitis (i.e. flesh-eating bacteria) when her second daughter was born, and had to have both her arms and legs amputated to survive. She highlighted key lessons for coping positively with difficult situations, namely; accept your situation as it is, because it cannot be changed. When you do you are able to move forward; don’t get stuck on asking “why me?”, just make do with what you have and look for the positive aspects in your situation (e.g. having the capacity to love your child); reappraise your situation positively by looking for the benefits; you are not good for your family if you are miserable; and derive strength from your support system (i.e. family, friends and professionals at the hospital/rehabilitation center).</p>
Gratitude journal	Writing exercises were effective in enabling learners to practice the learning topic (Dunst & Trivette, 2009; Niederhoffer & Pennebaker, 2002). To facilitate parents’ appraisal of their challenges from a positive perspective, parents were asked to consider their experiences in parenting a child with a disability, and to identify two things that they were grateful for. Parents needed to look for ways in which the experience enhanced their growth positively (e.g. made them more patient, flexible, etc.).
<p>Planning and practicing the communication of problems experienced in parenting their child with a moderate to severe communication disability, secondary to established disability</p>	<p>Parents were required to actively engage in using the new knowledge and skills for problem definition. They were encouraged to apply the information provided in the handout “Getting the help you need when talking to professionals. A simple 2-step plan”, to their own situation, and to practice communicating their problems and needs to the speech-language therapist to access the help that they needed.</p>
<p><b>Instructional materials - Handouts</b>          Getting the help you need when talking to professionals. A simple 2-step plan.</p>	<p>Handouts capture new knowledge and facilitate learners’ understanding and application (D’Zurilla &amp; Nezu, 1999).          The key principles that facilitate positive orientations to problems, and effective definitions of problems were captured in a handout to promote parents’ access to relevant ECCI. Parents could learn from the handout at</p>

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	their own pace, and monitor their own learning (Dunst & Trivette, 2009). Appendix S describes the development of the handout.
Motivational messages to facilitate positive problem appraisals	Parents were given three short motivational messages at the end of training on Day 2. The messages were intended to facilitate problem orientations as follows: Message 1 entitled “Sometimes” – identified different methods of managing stress (e.g. a smile, using the right words, taking a break, prayer) Message 2 entitled “Don’t get stuck on blame” – identified the negative effects of dwelling on blame. Message 3 entitled “It’s called mindset” – highlighted the power of beliefs in enabling or disabling individual’s positive functioning. The messages were downloaded from the internet, using Google search, and key words “inspirational quotes” and “inspirational messages for positive attitudes”.

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**\*Note:** All videos and PowerPoint slideshows were accessed from websites that were available for public use, at no cost,

Figure Q1 provides a schematic presentation of the philosophy and process that guided POD training.

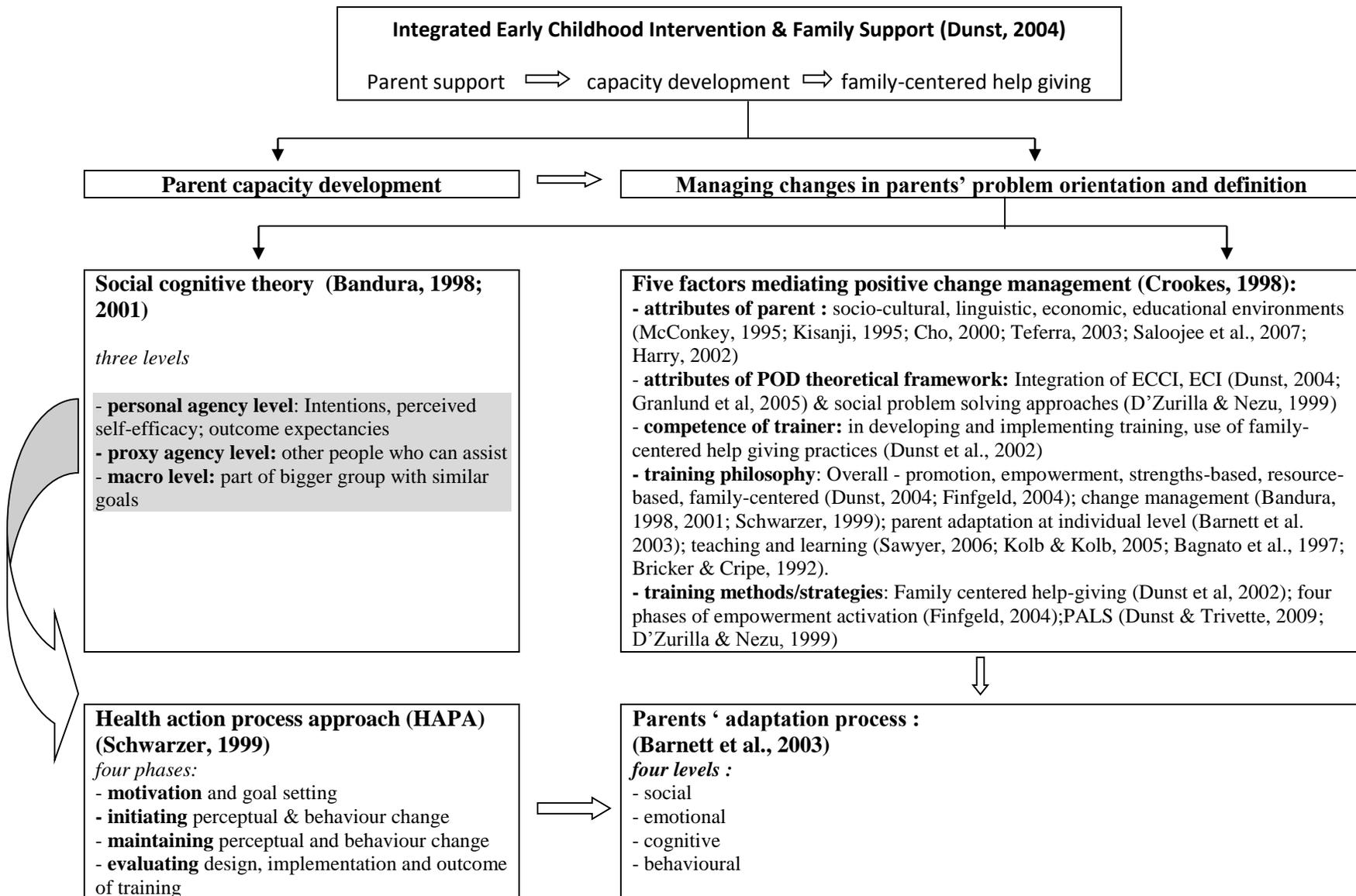


Figure Q1: Schematic presentation of the philosophy and process that guided POD training

## Appendix R

### Development and validation of POD training handout

**Motivation for using a training handout:** Training handouts can facilitate individuals' awareness and knowledge of values, behaviours and skills, and contribute to positive changes in use (Kulukulalani, Braun & Tsark, 2008). Research on instructional methods for teaching adults communication skills indicate large effect sizes for methods that included modeling and practice (Anderson & Sharpe, 1991; Cegala et al., 2000; Dunst & Trivette, 2009). Training handouts provide a relevant means to provide modeling through the use of examples, and to include practice, by prompting parents to think about, plan and write their responses in the handout (Cegala et al., 2000). Thus, a training handout was developed for this study, to facilitate parents' use of positive problem orientations and effective problem definitions when seeking help during ECCL.

#### Development and validation of POD handout

**(a) Aim of the handout:** To provide parents with information that would facilitate their use of positive problem orientations and effective problem definitions when communicating their problems and needs to speech-language therapists during ECCL.

**(b) Method:** The four-step protocol proposed by Kulukulalani et al. (2009) for developing culturally relevant brochures was very relevant for this study, and was thus adapted and used as the main framework to guide the development and validation of the handout. Table R1 outlines the steps and the development and validation process.

Table R1

*Four-step protocol used in developing and validating the POD training handout*

<b>Four-step protocol (Kulukulalani et al., 2008)</b>	<b>Application in this study</b>
1. Draft the handout Determine sources of information, message, format, and operationalize cultural and language/readability strategies.	Guidelines from the parent-professional communication intervention studies reviewed in Section 2.3.2 (Frederikson & Bull, 1995; McCann & Weinman, 1996; Cegala et al., 2000), Table 3 in Section 2.3.2, and studies from the broader health education literature (Kulukulalani et al., 2008; Daley, Cowan, Nollen, Greiner & Choi, 2009) were used to develop the training handout for this study. The intended message was to illustrate positive help-seeking attitudes and communication behaviours clearly in a format that was easy to read and understand by the majority of parents coming from diverse cultural, educational and socioeconomic backgrounds, and who could speak and understand English. The need for parents' proficiency in English is motivated for later in Section 3.4.2.1.1. Particular attention was thus given to creating an appealing layout; using culturally appropriate content and pictures; and simple language that was easily readable. It was also important that the handout accomplished three

<b>Four-step protocol</b> <b>(Kulukulalani et al., 2008)</b>	<b>Application in this study</b>
	<p>aims as recommended by Cegala et al. (2002), that is, (i) <i>provided information</i> that motivated parents to change problem orientations and definitions that did not facilitate their help seeking in ECCI; (ii) <i>provided examples</i> that illustrated appropriate orientation and definition behaviours; and (iii) <i>provided opportunities for parents to practice</i> the recommended problem definition skills,</p>
<p>2. Conduct technical review and obtain preliminary endorsement - consult with experts</p>	<p>The handout was reviewed by seven experts in the field of ECCI, as part of the broad process of validating the training program me before the main study. The social validation process is discussed in detail under expert review 3 in Section 3.4.1.2.2 and illustrated in Figure 4 in Chapter 3. With respect to the handout, expert reviewers were asked to evaluate the following: (i) to what degree the handout content achieved the intended aim, (ii) to what degree the handout was suitable for the intended sample of parents in terms of content, language level and readability; format, layout, pictures and photographs, visual illustrations of content, and length. Reviewers were provided with three documents, namely; a review sheet which outlined the aim and two sub-aims of the review (stated above); Table 1 (Section 2.3.2), which illustrated the proposed theoretical framework of parents’ problem orientation and definition for achieving effective and sustainable in ECCI outcomes; and the draft handout. The review sheet used a three-point rating system (0-2) to assess the two sub-aims. Ratings for sub-aim one: 0 = not achieved, 1= partly achieved, 2 = achieved; and sub-aim two: 0 = not suitable, 1= somewhat suitable and 2 = suitable). Reviewers had to indicate their concerns for scores rated 0-1, to facilitate revisions of the handout. Reviewers’ ratings indicated that the aim was achieved, and recommendations included making changes to some of the photographs to make it more representative of the majority of the parents in the study, to use the acronym “positive” to list positive orientations, and to make minor changes to the layout and language (e.g. use of the term attitude instead of orientation). All changes recommended were done.</p>
<p>3. Conduct consumer testing and reinforcement          - consult with providers          - consult with clients          - conduct revision and ensure final readability</p>	<p>The handout was evaluated by two speech-language therapists (i.e. providers) and two parents (i.e. clients) during pilot study 3 (Figure 3.2 in Chapter 3). The main aim was to assess the suitability of the handout for parents of children with moderate to severe communication disabilities (secondary to established disabilities), who accessed ECCI at public hospitals. Pilot study 3 was a component of the broad validation process for the training programme, and is described in detail in Section 3.4.1.2.2. Speech-language therapists and parents were evaluated separately and informed of the aim of the study and purpose of the handout, and provided with a copy of the handout and the review sheet used in expert review 3. They were requested to evaluate sub-aim two, as stated above for expert review 3, using the same rating scale. Both groups were satisfied that the handout was suitable for the intended sample of parents. The speech-language therapists recommended minor editorial changes, and these were implemented.</p>
<p>4. Conduct final review and endorsement</p>	<p>A final review of the handout occurred with two parents in pilot study 4, which established the validity and reliability of the overall research design</p>

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**Four-step protocol  
(Kulukulalani et al.,  
2008)**

**Application in this study**

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(Figure 4 in Chapter 3). Parents used the handout as intended, and found it very useful. The handout thus received final approval and no further changes were recommended.

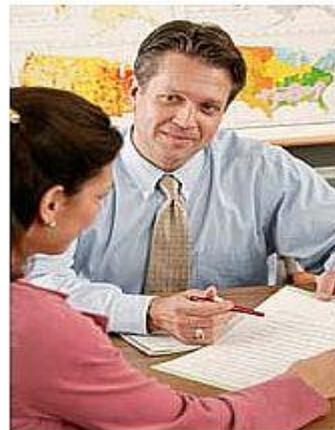
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## Appendix S POD training handout



# Getting the help you need when talking to professionals

*A simple 2-step plan for parents*



Developed by:  
Legini Moodley  
(University of Pretoria)  
**Contact details:** (H) 031-2091882 (W) 031-2607387  
Email: moodleyl@ukzn.ac.za



## Getting the help you need...

Getting help from professionals is not easy for many parents. Too often parents receive treatments that do not work. This makes you feel that professionals don't listen to you when you talk, or that professionals don't understand the problems that you experience in caring for a child who cannot speak properly.

### What can you do?

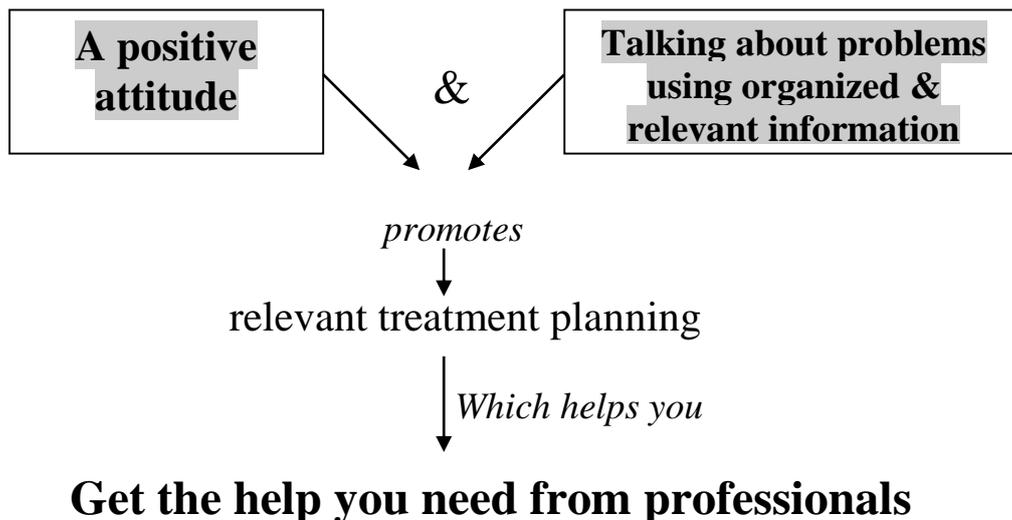
Learn a **simple 2-step plan** that teaches you *how to talk* to professionals:

**Step 1** involves *looking* at your child's problems with the right attitude.

**Step 2** involves *talking about your child's problems* in a way that makes it easy for professionals to understand what help is needed.

The information in this handout uses the 2-step plan to help you get the help that you need from your child's **speech therapist**.

### *Summary of the 2-step plan*



## Step 1: *Look at your child's problems with the right attitude*

Having a *positive attitude* towards your *child*, the *disability* and *yourself* helps greatly in getting the help your child needs.



### 8 steps to create a POSITIVE attitude...

<b>P =</b>	<p><b>- Problems are normal.</b> Everyone has problems. How you deal with problems is important.</p> <p><b>- Pay attention</b> to your child's general development (talking, walking, eating, playing etc).</p>
<b>O =</b>	<p><b>- Observe other children</b> who are the same age as your child / or who have a similar disability. If they talk (or walk, or eat, etc.) <i>far better</i> than your child – <i>it is a problem</i></p>
<b>S =</b>	<p><b>- See talking as an important skill</b> that your child needs to learn.</p> <p>Talking helps your child to: (i) get what she or he <i>needs</i>, (ii) <i>play</i> with others, and (iii) <i>learn</i> at school.</p>
<b>I =</b>	<p><b>“I can get help</b> for my child.”</p> <p>Believe in yourself.</p>
<b>T =</b>	<p><b>Take action</b> – now!</p> <p>Visit your local clinic or hospital. The doctor or nurse will help you to see a speech therapist.</p>
<b>I =</b>	<p><b>“I know that the treatment will help</b> my child.” Have faith in the treatment. It is planned especially for <i>your child and family</i>.</p>
<b>V =</b>	<p><b>View your situation</b> as something that <b>you can change</b> with the help of a professional.</p> <p>Don't get stuck on looking for causes or blame. If the disability cannot be cured, then changes can be made to people around your child or the environment. These changes can help your child and the whole family cope better.</p>
<b>E =</b>	<p><b>Everyday is an opportunity to learn more</b> about your child. Devote <b>time and effort</b> to help your child to be the best that she or he can be. Involve family, friends and organizations that can help you (e.g. religious organizations, parent support groups).</p>

**A positive attitude helps you to cope effectively!**

## Step 2: *Talking about your child's problems...*



To get the right treatment, you need to talk about your child's problems as you experience it at home (or any other place). This helps the therapist to understand the problem, and to choose a relevant method of treatment.

### **How should I talk about my child's problems?**

The best way is to:

- (1) Talk about your child's problem in an ***organized manner***.  
[i.e. *what is the problem, to whom; why is it a problem; what do you want from treatment*].
- (2) Provide ***information that is relevant*** to your child's problem.  
[i.e. *specific to your child's problem; detailed; with many examples*]

The table shows you how to *organize* your information along the **3 important points**, and outlines *information that is relevant* for each point.

Use the 3<sup>rd</sup> column in the table to write your own information.  
The 4<sup>th</sup> column tells you how your information helps the therapist to plan and provide treatment that will address your problems.



<b>Organization of information</b> <i>(what is the problem, why, what do you want from treatment)</i>	<b>Relevant Information</b> <i>(specific, detailed, with examples)</i>	<b>Write down your own information here</b>	<b>How information helps treatment planning</b>
<b>Begin with...</b> <b>1. What is the problem?</b>	<ul style="list-style-type: none"> <li>- State what you think the <b>problem</b> is.</li> <li>- Be specific</li> <li>- Give details</li> <li>- Give examples e.g. My child is not talking properly for his age. He only says two words (<i>state the words and what it means</i>)</li> <li>- Talk about your child's talking difficulties AND other problems that you have. (e.g. no money).</li> </ul>	<b>My child's biggest problem is...</b>	<ul style="list-style-type: none"> <li>- Identifies what is a problem for you and your family.</li>   <li>Talking about other problems allows the therapist to have a full understanding of your situation – so that appropriate referrals can be planned.</li> </ul>
	<ul style="list-style-type: none"> <li>- State what you think is the <b>cause of your child not talking properly</b>. e.g. He was born with cerebral palsy. If you don't know what the cause is, say so.</li> <li>- Explain <b>what happened from the time he was born until now</b>.</li> </ul>	<b>My child was born with ...</b>  <b>The problem started when ...</b>	<ul style="list-style-type: none"> <li>-Helps the therapist understand how the problem began.</li>   <li>- Tells the therapist if you understand the problem the same way that s/he does.</li> </ul>
	<ul style="list-style-type: none"> <li>- Talk about everything that you did to help him (e.g. taking him to doctors, etc.)</li> </ul>	<b>Since my child was born, I tried to help him by ...</b>	Therapist understands what has been done so far to treat the problem.

<b>Organization of information</b> <i>(what is the problem, why, what do you want from treatment)</i>	<b>Relevant Information</b> <i>(specific, detailed, with examples)</i>	<b>Write down your own information here</b>	<b>How information helps treatment planning</b>
What makes it difficult for your child to talk properly	- Discuss any <i>specific problems</i> with : (i) the child's body parts and/or how it works (ii) other people (e.g. family members), (iii) the home, community or school etc that you think makes it difficult for your child to be with others and learn. Give examples. e.g. He can't move his tongue; people tease him.	<b>My child has problems with ...</b>  <b>Other people treat him ...</b>  <b>At home he finds it difficult to ...</b>	Identifies important factors that treatment needs to focus on.
Who finds it a problem?	- Identify people who complained or asked you about your child's talking. Give examples. e.g. It is a problem for me, my family, neighbours, the teacher etc	<b>The following people find his talking a problem ...</b>	- Identifies who is affected by the problem. - Gives some idea of how bad the problem is.

<b>Organization of information</b> <i>(what is the problem, why, what do you want from treatment)</i>	<b>Relevant Information</b> <i>(specific, detailed, with examples)</i>	<b>Write down your own information here</b>	<b>How information helps treatment planning</b>
<b>2. Why is it a problem?</b>	- Discuss difficulties that you and the family experience, because of your child's poor talking. Use examples to explain. e.g. We don't know what he wants when he cries. Is he hungry or in pain?	<b>His talking is a problem because...</b>	- Tells the therapist about specific situations that treatment should change.
What makes it difficult for you to help your child to talk?	Identify things that prevent you from helping your child. Give examples.  e.g. Your lack of knowledge or skills; your attitude towards disability; poor health; limited time due to other demands; child's behaviour problems; no money, transport problems etc	<b>I find it difficult to teach him to talk because...</b>	-Tells the therapist about what to include in treatment, and how to treat it. -Also guides referrals to other health workers. -Helps the therapist to plan treatment around things that are difficult for you.
<b>End 3. What do you want from treatment?</b>	- Identify specific behaviours that need to be <i>changed or added</i> to make it easier for you to take	<b>I would like him to be able to say ....</b>	- Tells the therapist about particular behaviours that <i>you</i> want

<b>Organization of information</b> <i>(what is the problem, why, what do you want from treatment)</i>	<b>Relevant Information</b> <i>(specific, detailed, with examples)</i>	<b>Write down your own information here</b>	<b>How information helps treatment planning</b>
	care of your child. Give examples. e.g. I want him to say what he wants OR His father wants him to point to what he wants if he can't talk, etc.	<b>His</b> ( <i>any other person in the family</i> ) <b>would like him to say ...</b>	treatment to change.  - Tells the therapist about behaviours that <i>other people</i> want treatment to change.
Why do you want these changes?	State how these changes will make life at home better for you and the family. Give examples. e.g. I can feed him if he is hungry or give him his medicine if he is in pain.	<b>If he can say this it will make it easier for me to ...</b>	Helps you and the therapist in checking to see if treatment is working.

**\*NOTE:** All photographs that were used in the handout were obtained from websites that provided free access for public use.

## Appendix T

### Development and validation of POD training videos

**Motivation:** Real-life examples, role-playing/simulations and instructional videos are effective instructional methods to illustrate new learning topics (Dunst & Trivette, 2009). Thus, all three methods were selected to illustrate to parents the effects of positive problem orientations and effective problem definitions on parents' help seeking in ECCI.

#### Development and validation of POD training videos

**(a) Aims of the videos:**

- To provide learning opportunities for parents to observe good and poor help-seeking behaviours specific to problem orientation and definition of problems.
- To model interpersonal and communication skills that facilitated and inhibited good problem definition behaviours, and thereby promoted or hindered help-seeking in ECCI.

**Positive interpersonal skills included:** active interest and engagement in intervention, confidence, and respect for professionals, yet understanding the principles of equal partnership.

**Good problem definition behaviours included parents' knowledge and/or communication skills in the following:** the child's communication skills; history of the problem from onset; previous assessment and treatment, and outcomes; results of tests/assessments done; describing challenges as they occurred in the home or other context, using examples to illustrate; clearly stating what changes are required in the child's behaviour or environment to facilitate the family's positive functioning; knowledge of the role of the professional, and tailoring information for that professional (e.g. SLT).

Negative problem orientations and poor problem definition skills included attitudes and skills that were opposite to those described above. For example, no interest in seeking help; displaying poor knowledge of the child's communication behavior.

**(b) Method:** Three training videos were developed. The main framework of the protocol by Kulukulalani et al. (2009) that was used to develop the training handout, was found to be applicable for developing and validating the training videos. The steps were adapted to include a further step to develop the videos, after the scripts were approved. Table T1 outlines the five steps and the development and validation process.

Table T1

*Five-step protocol used in developing and validating the POD training videos*

<b>Five-step protocol</b> (adapted from Kulukulualani et al., 2009)	<b>Application in this study</b>
1. Draft the video scripts. Determine sources of information, message, format, and operationalize cultural and language strategies.	Guidelines from the parent-professional communication intervention studies reviewed in Section 2.3.2 (Anderson et al., 1987; Lewis et al., 1991) were used. The intended message was to illustrate positive help-seeking attitudes and communication behaviours clearly in a visual format that was easily understood by the majority of parents coming from diverse cultural, educational and socioeconomic backgrounds, and who could speak and understand English. The need for parents' proficiency in English is motivated for later in Section 3.4.2.1.1. Particular attention was thus given to the selection of the parent for video one, and the creation of scripts for videos two and three, as it was important that parents were able to relate to the content and people in videos.
2. Conduct technical review and obtain preliminary endorsement - consult with experts	An initial review of the aims and scripts of the three videos was conducted, <i>before</i> the training videos were developed. The aims of the training programme, aims of the training videos, overview of the content required for Video 1, and the proposed scripts of Videos 2 and 3 were reviewed by the seven experts in the field of ECCI, as part of the broad process of validating the training programme before the main study. The social validation process is discussed in detail under expert review 3 in Section 3.4.1.2.2 and illustrated in Figure 4. The reviewers were requested to evaluate whether the aims and proposed content for the training videos were relevant to meet the aims of the training programme. The outcome was very positive and all seven reviewers rated the aims and content as appropriate. No changes were suggested.
3. Develop training videos	A brief description of the development of each video, as well as the approved scripts are provided.  (i) Video 1: A confident parent sharing her positive experiences of ECCI Aim: To demonstrate parenting beliefs that facilitate positive problem orientations, specifically: <ul style="list-style-type: none"> <li>• problem perception - recognize child's communication problems and ECCI as a resource.</li> <li>• personal control - display strong belief in her own capacity to assist the child, takes an active role during intervention, has positive and realistic expectations about ECCI in helping the child, parent and family to cope, and experiencing positive outcomes from ECCI.</li> <li>• problem appraisal – accept the child, view the child's disabilities as similar to any other problem that the family must manage.</li> </ul> Method: Resident SLTs working in ECCI programmes at four public hospitals in Kwa-Zulu Natal were contacted telephonically, after permission for the study were obtained from the Department of Health and head of the hospitals. They were informed telephonically and through email documentation about the aims of the study; content of the training programme; the need for video-recording a consenting parent who was: (i) currently attending ECCI, (ii) displayed positive orientations towards the child's severe communication disability secondary to an established disability, and towards ECCI; and (iii) experiencing positive

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outcomes from ECCI. To facilitate the experimental group parents' ability to relate to the video, the parent had to (iv) share a similar cultural, linguistic, education, and economic background as the majority of the mothers in the study; and (v) typify the characteristics of a "mother warrior" in the local context. Three parents were identified, but only one parent was available during the period scheduled for video-recording. Informed consent forms were signed and video-recording occurred on a day that the parent had a scheduled ECCI appointment at the hospital. The mother was again informed about the aim of the study and purpose of the video, and asked to share her story about her child's disability, highlighting problems experienced and her coping strategies, and to conclude with the benefits she derived from ECCI. The video-recording was done by a trained technician and the duration of the video was approximately five minutes.

(ii) Video 2: Simulation of a parent with positive orientation and good problem definition skills

Aim: To illustrate a parent displaying positive problem orientations and effective problem definition skills, communicating her problems and needs when seeking help from the SLT.

Method: A script was developed and designed to illustrate the key principles of: (i) positive orientations in the five dimensions of problem orientation (i.e. problem perception, problem attribution, personal control, problem appraisal and commitment of time and effort); and (ii) good problem definition skills in the two dimensions of problem definition (i.e. organization and relevance of information) – as outlined in Table 1 (Section 2.3).

The model selected to play the part of the parent was of similar age, culture and language background as the majority of parents in the main study (i.e. Black, second language English speaker). She was a 28 year old mother, had an educational background and could relate to the aim and purpose of the video. The researcher modeled the part of the SLT. The script was rehearsed six times before the intended outcomes were reached. The video-recording was done by a trained technician and the duration of the video was approximately five minutes.

Outline of the script describing the parent's definition of problems and needs:  
Beginning: My son, Bheki is not talking properly. He's 2 years old, but all he does is make sounds. Other children his age are talking. My neighbour's child is the same age, and he talks in short sentences. I noticed that Bheki was different from his sisters. He did not make a lot of sounds and noises when he was a baby. He was very quiet. I told the nurses at the clinic when he was 6 months old, they said that he will learn. He's now 2 years – and I am worried. I want him to get help for his talking and walking.

My family, neighbours and people at church all ask me – what is wrong with him – why can't he talk? He is naughty because he cries a lot. They don't understand.

Bheki was born with cerebral palsy. *Describes pregnancy and birth.*

It is very difficult – when he cries – I don't know what he wants, whether he is in pain. He sometimes cries a lot. I have other work to do, and it is very frustrating. I also have to feed him, otherwise he chokes. He can't eat or drink

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by himself. I have to be careful what I feed him. He only eats soft food like mashed pumpkin, potato, custard. All his food must be mashed. But I love him. He is my child. I will do anything for him. We don't have much money. My husband works as a labourer, and we have 2 older daughters. They are going to school. One is 6 years, and the other is 8 years. Life is hard. I use pictures from the paper and old magazines to show him. He loves it! I also give him an old plastic cup, a small ball etc. to play with. He can't hold the ball. His hands are a problem because of the cerebral palsy. His legs too. I teach him to talk, but he can't. I know that he understands me sometimes because he smiles. When I sing to him, he loves it. He watches TV. I'm not sure if he understands. His sisters play with him, and help me look after him. We include him in everything and we take him everywhere in his pram. He is important to us. We see him as a special gift from god. God chose us to look after him. We know that He will help us look after him. I took him to the clinic, and the nurse asked me to come to you. She said that you will help me.

Middle: I am willing to do whatever I can to help him. I want him to talk or point at what he wants. Whatever he can, to tell us what he wants. Talking is very important for him. He can then tell us what he wants to eat, if he is tired or his head is paining, if he wants to go to the toilet. I would really like him to say this. Napkins are so expensive. If he can say this it will really be nice. He can also play with the other children. Now, the other children don't want to play with him because he can't talk like him.

End: Now, I don't know how to teach him to talk. I want to learn how to do this. He must also learn to listen and pay attention, so he can learn.

I want him to go to a special school where they can teach him...but money is the problem. I am going to talk to my pastor, to see if the church can help us. He also needs a special wheelchair. I've seen other children with his problem, using special wheelchairs. I want to know how I can get one for him.

(iii) Video 3: Simulation of a parent with negative problem orientation and poor problem definition skills

Aim: To illustrate a parent displaying negative problem orientations and poor problem definition skills, communicating her problems and needs when seeking help from the SLT.

Method: A script was developed and designed to illustrate the key principles of: (i) negative orientations in the five dimensions of problem orientation (i.e. problem perception, problem attribution, personal control, problem appraisal and commitment of time and effort); and (ii) poor problem definition skills in the two dimensions of problem definition (i.e. organization and relevance of information) – as outlined in Section 2.3.1.

The model selected to play the part of the parent was a speech-language therapist of similar age, culture and language background as some parents in the main study (i.e. Indian, first language English speaker). She was a 25 year old mother, and could relate to the aim and purpose of the video. The researcher modeled the part of the SLT. The script was rehearsed four times before the intended outcomes were reached. The video-recording was done by a trained technician and the duration of the video was approximately five minutes.

Outline of the script describing the parent's definition of problems and needs:

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	<p>Beginning (Single mother of a child with a suspected hearing loss) : I was told to come see the speech therapist. I'm not sure why. My child talks okay. <i>(According to referral letter from the clinic nurse, the child is three years old and only saying a few one word utterances, e.g. "ma")</i>.</p> <p>I feel that he will learn in his own time. My sister took a long time to talk. She was five years old when she started to talk. So you see, he is only three years. He's still small. He should be left to learn on his own. I'm just wasting my time coming here. I told the nurse.</p> <p><i>(Mother displays a "don't care" attitude. Does not recognize that the child has a problem)</i></p> <p>Middle: I have so many problems. I am sick <i>(talks about her many other problems, e.g. her illnesses, she needs money to go to the doctor for her own problems etc.)</i>.</p> <p>I'm not working. I'm sick myself and I don't have much time to spend with him. He is left to do what he wants. He sits in front of the TV most of the time. I don't know whether he knows what is happening.</p> <p>You should know best if there is a problem. If there is, then you can fix the problem.</p> <p><i>(parent presents information in a disorganized format. No clear development of the story. Moves from one aspect to another making it very difficult to follow. Not able to provide examples to illustrate his talking.)</i></p> <p>END: You can talk to him and see for yourself if anything is wrong with his speech, He's quiet, that's all.</p> <p><i>(Not able to provide specific information, that is, date of birth, developmental milestones. Is very vague. Keeps saying "I don't know" or "I'm not sure. You need to speak to the nurse."</i></p> <p><i>(Does not say what she wants from treatment because she does not recognise that communication is a problem).</i></p>
<p>4. Conduct consumer testing and reinforcement - consult with providers - consult with clients - conduct revision and ensure final suitability</p>	<p>The videos were evaluated by two SLTs (i.e. providers) and two parents (i.e. clients) during pilot study 3 (Figure 4). The main aim was to assess the suitability of the videos as training material to facilitate parents' use of positive problem orientation and problem definition skills during ECCL. Pilot study 3 was a component of the broad validation process for the training programme, which is described in detail in Section 3.4.1.2.2. Speech-language therapists and parents were evaluated separately and informed of the aim of the study, training programme and purpose of each training video. They were asked to watch each video and evaluate its suitability in achieving the training aims, using a three-point rating scale: (i.e. 0 = not suitable, 1= somewhat suitable and 2 = suitable). Reviewers had to indicate their concerns for scores rated 0-1, so that the videos could be revised if required. Reviewers' ratings in both groups indicated that all three training videos were suitable, and no revisions were recommended.</p>
<p>5. Conduct final review and endorsement</p>	<p>A final review of the training videos occurred with two parents in pilot study 4, which established the validity and reliability of the overall research design (Figure 4). Parents watched the training videos as intended in the training programme, and training outcomes were positive. Parents' feedback on the videos as training strategies was also positive. The training videos thus received final approval before the main study.</p>

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## Appendix U

### Detailed plan outlining the design and implementation of the training programme

Parent Competency & Learning Domain	Training Aims & Motivation	Session and Content	Training methods & equipment	Evaluation
<p><b>Phase 1</b>            (Schwarzer, 1999, 2001; Singer &amp; Irvin, 1989; D’Zurilla &amp; Nezu, 1999, 2010; Granlund, 2005; Dunst &amp; Trivette, 2009; Bryan et al., 2009)</p> <p>1. To <i>strengthen parents’ motivation to participate</i> in the study by ensuring that the participants and trainer have a common understanding of the problems parents face in parenting young children with moderate to severe communication disabilities that are secondary to established disabilities, the need for parents to be skilled help-seekers, and the need for parent support to enhance help-seeking skills. Parent volunteers already imply some level of motivation present.</p> <p><b>Motivation:</b></p> <ul style="list-style-type: none"> <li>- Parents must experience a minimum level of concern about their role as consumer/decision-maker and the need for competence in managing challenges by accessing relevant help from professionals, before they start contemplating the benefits of participating in the training programme</li> <li>- Parents make assumptions about the consequences of disability before they contemplate whether they should take any action. The validity of these assumptions need to be discussed in the light of current research, policies, and intervention available to families of children with moderate to severe communication disabilities, secondary to established disabilities.</li> </ul>				
<b>Day 1 Session 1: 9.00am-10.30am 90 minutes</b>				
<p><b>DV1: Problem Orientation</b></p> <p><b>1.1. Problem Perception</b></p> <ul style="list-style-type: none"> <li>- Parent will demonstrate motivation by displaying a positive attitude to training as s/he gains or strengthens understanding of training benefits in enhancing his/her help-seeking and positive functioning during ECCI</li> </ul>	<p><b>Introduction to Day 1</b></p> <ul style="list-style-type: none"> <li>- To introduce the participants to each other (trainer, training assistant and parents)</li> <li>- To contextualize the training within help-seeking and help-giving/collaborative problem-solving between parent and professional during ECCI.</li> <li>- To reiterate the problems that parents experience in parenting young children with communication and established disabilities, and</li> </ul>	<p>Commence with welcome message and brief introductions of trainer, assistant and participants. All participants to have name-tags (first names).</p> <p>A brief outline of the motivation for and focus of training on promoting parents’ help-seeking to access the support needed, in relation to parenting challenges and stress experienced by many parents of children with disabilities. The significance of parents’ role as caregiver, change agent, decision-maker and consumer is emphasized. Using information from the literature and parents’ pre-training responses, the common problem of parents’ not getting the support needed from professionals is reiterated. Reasons included (i) professionals not listening to parents’ concerns and instead providing what they felt was important;</p>	<ul style="list-style-type: none"> <li>• Welcome &amp; introduction using power-point slides (5 min)</li> <li>• Laptop: HP, Compaq 6720s</li> <li>• Projector: Optoma, EW610ST</li> <li>Both equipment used throughout training.</li> </ul>	<ul style="list-style-type: none"> <li>• Pre-and-Post Training Interview Schedule</li> <li>• Informal evaluations during training</li> <li>• Training session evaluation (Appendix V)</li> <li>• General evaluation (Appendix W)</li> </ul>

Parent Competency & Learning Domain	Training Aims & Motivation	Session and Content	Training methods & equipment	Evaluation
<p><b>Learning Domains:</b>  <i>Parent's beliefs, values regarding the need for parent training</i></p>	<p>accessing help that meets parents' needs.            - To emphasize parent's role as caregiver and change agent, the significance of their problem solving skills in this regard, specifically problem orientation and problem definition.            Implications for their role as help-seeker during ECCI (i.e. consumer /decision-maker), and achieving positive outcomes (Granlund et al., 2005; Dunst et al., 1994; Dunst, 2004)</p>	<p>and/or (ii) parents not confident to ask for the help that they needed, or holding onto the belief that professionals were the experts and parents should remain passive and listen during consultations.</p> <p>1.1 Parents encouraged to share their parenting experiences to facilitate rapport amongst participants, and recognition of the similarity in their concerns and challenges, and to also minimize the stigma associated with disability (Finfgeld, 2004; Neiderhoffer &amp; Pennebaker, 2002).</p> <p>- Key challenges are noted in conjunction with information from pre-training interviews &amp; literature. For example: specialized medical, educational and rehabilitative care; increased financial burdens, minimal family income etc (Harris &amp; McHale, 1989; Sloper; 1999; Baxter et al., 1995; Neely-Barnes &amp; Dia, 2008).</p> <p>From pre-training interviews many parents asked the following questions:            i. How do I cope with the challenge of raising a child with a disability, in a context with limited resources, for example, money, time, health/energy, social support. etc.?            ii. Do I have the right attitude, knowledge and skills to cope with daily care-giving, getting the help I need, talking and working with health and education professionals?            iii. What can I do to improve my knowledge, attitude and skills to cope better?</p>	<ul style="list-style-type: none"> <li>• Parents relate individual experiences in parenting their child with a communication disability secondary to an established disability (Finfgeld, 2004; Woods &amp; Lindeman, 2008) (5 min per parent=75min)</li> <li>• Empathetic listening, acknowledgement &amp; constructive feedback regarding concerns. (Finfgeld, 2004; Dunst &amp; Trivette, 2009; D'Zurilla &amp; Nezu, 1999; Woods &amp; Lindeman, 2008)</li> <li>• Group discussion to summarize /consolidate challenges, illustrate that other parents are facing similar or more severe challenges,</li> </ul>	

Parent Competency & Learning Domain	Training Aims & Motivation	Session and Content	Training methods & equipment	Evaluation
	<p>- To emphasize the need for parents' to be proactive in accessing parent support in help seeking.</p>	<p><b>Tea-break: 10.30am-11.00am 30 minutes</b></p> <p><b>Day 1 Session 2: 11.00am-12.45pm 105 minutes</b></p> <p>The need for parents to be proactive and to acquire the resources needed for effective coping and functioning is emphasized. Parent does not have all the solutions, so becoming an effective help-seeker is critical. Approaching and communicating with professionals to get the help/support needed is important to facilitate positive functioning of the child, parent and family.</p> <p>Five resources that can facilitate parents' coping and adaptation according to (Folkman et al., 1979):</p> <ul style="list-style-type: none"> <li>- health and energy (physical and emotional well-being)</li> <li>- supportive social networks</li> <li>- access to utilitarian resources (income, social grants, ECI)</li> <li>- positive general and specific beliefs (self-efficacy, personal control, religious faith)</li> <li>- problem solving           <ul style="list-style-type: none"> <li>▪ The significance of parents' problem solving skills in facilitating help-seeking and thus parenting of a child with a disability is highlighted (specifically problem orientation and</li> </ul> </li> </ul>	<p>facilitate recognition that some parents have developed positive ways to manage challenges. (10 min)</p> <ul style="list-style-type: none"> <li>• Lecture using power-point slides (Dunst &amp; Trivette, 2009; Finfgeld, 2004; Woods &amp; Lindeman, 2008)</li> <li>• Cognitive re-framing (i.e. providing new information to provoke changes in thinking about current situation and functioning) (D'Zurilla &amp; Nezu, 1999, 2010). See Appendix Q for details on method) (10 min)</li> </ul>	

Parent Competency & Learning Domain	Training Aims & Motivation	Session and Content	Training methods & equipment	Evaluation
		<p>problem definition). The need for parent support is established.</p> <ul style="list-style-type: none"> <li>▪ Brief overview of the help-seeking process, as illustrated in Figure 1 and Table 1.</li> </ul> <p>- Identify the crucial role that parents play as <i>decision maker &amp; information provider</i> during ECCI, and the need for parents to have facilitating attitudes to initiate help-seeking, and knowledge and skills in communicating important information to professional to access the help needed. Both aspects are mediated by parents' problem orientation and problem definition skills.</p> <p>- Parents' beliefs and assumptions regarding disability, especially communication disabilities. Expected outcomes derived from cultural beliefs and parents' experiences, shape decision-making.</p> <p>- Brief information on:</p> <ul style="list-style-type: none"> <li>• the government's health and education policies regarding disability, especially free health care for children 0-6 yrs (NDP, 2011, DSD, DWCPD &amp; UNICEF, 2012)</li> <li>• ECI &amp; ECCI facilities available and the need for parents to work with health and education professionals like speech-language therapists</li> <li>• significance of children's communication skills for overall social, academic, and vocational achievements (Rossetti, 2001)</li> </ul> <p>- Focus of training on problem orientation and problem definition, and significance in accessing relevant, effective and sustainable ECI services</p>		

Parent Competency & Learning Domain	Training Aims & Motivation	Session and Content	Training methods & equipment	Evaluation
	<p>- To set specific and realistic training goals in keeping with the aim of the study and needs identified in the pre-test interview schedule</p> <p>- To enhance parent's belief in his/her own capability in learning and demonstrating the attitudes, knowledge and skills that are targeted in the training</p> <p><b>Motivation</b>            Training goals must be explicitly stated in order to facilitate the evaluation of training outcomes (Saunders et al., 2009).</p> <p>Parents must believe in their own capacity to act as decision-maker/problem solver in accessing the resources required to competently manage problems experienced in parenting their child. The parent's <b>self efficacy</b> is the most influential</p>	<p>- versatility of skills in problem orientation and problem definition for parents daily life</p> <p>The following goals are identified:</p> <ul style="list-style-type: none"> <li>• For parents to demonstrate positive orientations to problems experienced in parenting child with disability</li> <li>• For parents to demonstrate skills in problem definition when accessing ECCI services</li> </ul> <p>The significance of self-efficacy, that is, parent's belief in his/her own learning capabilities, as a parent who does not believe in his/her learning capabilities will not adopt, initiate and maintain the specific competencies targeted in the program me .</p>	<ul style="list-style-type: none"> <li>• Discussion using power-point slides</li> <li>• Modeling. Nick Vujicic you-tube video – “Are you going to finish strong?” (see Appendix Q for overview of content) (5 minutes)</li> <li>• Guided reflection and group discussion on strategies that he used to value and believe in himself. (i.e. persevere, don't give up no matter how difficult the problem, you are important; humor – look for funny aspects in difficult situations). Video is intended to provoke change in parents' perspective –</li> </ul>	

Parent Competency & Learning Domain	Training Aims & Motivation	Session and Content	Training methods & equipment	Evaluation
	<p>motivational factor and strongest predictor of behavioural intentions. (Schwarzer, 1999; 2001)</p> <p>- To outline the training format for the duration of the programme in terms of content, ambiance, training methods, and after session evaluation.</p> <p><b>Motivation</b></p> <p>- Parents must have an overall understanding of what will be offered during training</p> <p>- Parent and professionals expectations from each other need to be clear to prevent misunderstanding regarding training goals, content and process</p>	<p>Briefly discuss :</p> <ul style="list-style-type: none"> <li>- Overview of training goals and content to be covered from Day1-Day 4</li> <li>- Training ambiance/mood: trust, respect, mutual learning between trainer and parents, value everyone's contributions, empowerment, nurturing, open &amp; honest discussions &amp; sharing of information, no judgements, free to ask questions (Dunst &amp; Trivette, 2009; Woods &amp; Lindeman, 2008).</li> <li>- Training will be video-recorded for research purposes. Parts of the recordings may be shown at professional development forums to illustrate the need for parent support and to support research outcomes. Parents' names and intervention sites will not be disclosed.</li> <li>- Training methods include individual/group discussions, videos, power-point slideshows, homework assignments, role-plays, etc. Parents must feel safe and comfortable to share experiences, parents' individual identities will not be disclosed when reporting on the training. Homework assignments form an integral part of training, and need to be</li> </ul>	<p>there are people with more difficult challenges than mine. Link with parents' stories presented in session 1 as well, to illustrate this point (Taylor, 1983). (10minutes)</p> <p>• General Discussion (5 minutes)</p>	

Parent Competency & Learning Domain	Training Aims & Motivation	Session and Content	Training methods & equipment	Evaluation
		<p>completed by participants, as noncompliance may affect their learning outcomes</p> <ul style="list-style-type: none"> <li>- Discuss purpose of evaluation sheets in assisting trainer to plan relevant training sessions, and the need for parents to complete sheets after each day's training. Parents must also complete an overall evaluation form at the end of training. Evaluation sheets are easy to follow, and will not take more than 5 minutes to complete.</li> <li>- At the end of each day, lucky draw (pamper-packs sponsored by a group of mothers); collect transport money and gift for child.</li> </ul>		
<p><b>Phase 2</b>            To <i>initiate</i> attitude and behaviour changes in parents' problem orientations and problem definition</p> <p><b>Motivation</b>            Changes in parents' orientation to and definitions of problems must be carefully planned, initiated and maintained, and self-regulatory processes play a critical role (Schwarzer, 1999, 2001). In addition, it is important that training strategies that target changes in behaviour are predicated on changes in participants' awareness and attitudes (Peter, 1989). Thus, parents' attitudes to problems were targeted first, followed by problem definition behaviours.</p>				
<p><b>Parent will demonstrate a positive problem-solving mindset (orientation) by demonstrating the following:</b></p>	<ul style="list-style-type: none"> <li>- To facilitate parents' awareness of the dimensions of problem attribution, personal control, specifically self-efficacy, and problem appraisal</li> </ul>	<p><b>Day1: Session 2 continued</b></p> <p>Problems are a normal part of life. Some problems are more severe than others. How do parents cope positively with difficult problems?            Parents to read the story of "the warrior mum"</p>	<ul style="list-style-type: none"> <li>▪ Image-making through homework assignment. Case study – parents to read the story of "Meet a mother warrior". (see Appendix Q for overview of content)</li> </ul>	<ul style="list-style-type: none"> <li>• Pre-and-Post Training Interview Schedule</li> <li>• Informal evaluations</li> </ul>

Parent Competency & Learning Domain	Training Aims & Motivation	Session and Content	Training methods & equipment	Evaluation
<p><b>Perception of Emotions</b> - awareness of emotional responses that may facilitate or</p>	<p>Conclude session</p>	<p><b>12.45-1.00pm</b> Parent evaluation of Day 1, lucky draw, give parents' transport money &amp; gift for their child.</p>	<ul style="list-style-type: none"> <li>• Guided reflection. Parents to consider: what did she do to cope positively? Write down answers at the end of the story. For discussion on Day 2.</li> </ul> <p>Training session evaluation form, transport money, gift (juice bottle), luck draw pamper packs</p>	<p>during training (e.g. homework)</p> <ul style="list-style-type: none"> <li>• Training session evaluation (Appendix V)</li> <li>• General evaluation (Appendix W)</li> </ul>
		<p><b>Day 2 Session 1 : 9.00-10.30am 90 minutes</b></p>		
	<p><b>Introduction to Day 2</b> - To summarize the training on Day 1; identify parents' experiences of training; provide trainer's feedback (own experience and parents' evaluation).  - To identify the training goals for Day 2  - To discuss the significance of emotions in facilitating and inhibiting the recognition of problems</p>	<p>Key learning points of Day 1 are summarized, namely, parents sharing their own experiences of challenges, and the main points of the lecture. Trainer will acknowledge parents' courage and confidence in sharing information.</p> <p>The main focus of Day 2 is to expose parents to positive, healthy ways of conceptualizing and approaching problems in general and the child's disability in particular, to facilitate positive functioning of the child, parent and family.</p> <p>Information on becoming more aware of negative feelings and using this awareness as a cue to observe the environment and monitor parental behaviour in an attempt to recognize problems. For example, you feel helpless/frustrated when</p>	<ul style="list-style-type: none"> <li>▪ Informal discussion</li> <li>▪ Acknowledge parents' commitment and courage (Woods &amp; Lindeman, 2008) (5 min)</li> <li>▪ Lecture using power-point slides (5 minutes)</li> <li>▪ Review of homework assignment – overview of story of warrior</li> </ul>	

<b>Parent Competency &amp; Learning Domain</b>	<b>Training Aims &amp; Motivation</b>	<b>Session and Content</b>	<b>Training methods &amp; equipment</b>	<b>Evaluation</b>
inhibit the recognition of a problem	<p><b>Motivation</b>            Emotions play an important role in facilitating or inhibiting problem solving. The two sources of emotional arousal that are relevant for parents are: (1) the actual problematic situation, and (2) the beliefs, appraisals, and expectations regarding their child's disability and their ability to solve it (problem orientation mind-set). Positive affect (e.g. hope), in general, is likely to facilitate problem solving and change behaviour, whilst negative affect (e.g. fear, disappointment, anger) is likely to inhibit performance (D'Zurilla, 1986; D'Zurilla &amp; Nezu, 1999; Braswell, 1991).</p>	<p>your child cries because you don't know what is wrong when s/he cries. (problem is therefore, child's inability to communicate needs)            - managing negative emotions in constructive ways so that it promotes positive functioning of the child, parent and family. For example, instead of ignoring or denying the feelings, seek help by discussing the problem with family/ taking the child to the clinic/hospital for help.</p> <p>When the stressful situation is relatively stable or unchangeable, for example, parenting a child with an established disability, then parents need to adopt realistic problem solving goals like (i) minimizing emotional distress and/or maintaining or increasing feelings of self-worth (D'Zurilla, 1986). The latter can be accomplished through hobbies, social support, exercise, etc (discussed later in session 2)</p> <p>Emphasize the concept "warrior mum" – cultural meaning of "warrior" for South African Black &amp; Indian- a strong person. The concept will be reinforced throughout the training.</p>	<p>mum, cultural meaning of "warrior", and discussion of how she managed her feelings when she had to undergo surgery to amputate her limbs. (10 minutes)</p> <ul style="list-style-type: none"> <li>▪ Guided reflection &amp; problem-solving group discussion – parents encouraged to think about how they feel when they encounter parenting or other problems, to describe these and discuss how they currently manage it. What would be constructive ways of managing it Consider lessons learned from you-tube video (Day 1), as well. (10 min)</li> </ul>	
<p><b>Perception of the nature of problems</b>            - awareness that difficult problems can be controlled or managed</p>	<p>- To facilitate parents' understanding of problems in general, that is, controllable and uncontrollable problems. Training focuses on the management of problems that are uncontrollable (e.g.</p>	<p>- Differentiate between problems that can be easily controlled and removed (e.g. child who is sick with flu can receive treatment that stops it), versus problems that cannot be removed (e.g. child's established disability). Consider in relation to the warrior mum story and you-tube video (D'Zurilla &amp; Nezu, 1999)</p>	<ul style="list-style-type: none"> <li>▪ Lecture using power-point slides (10 min)</li> <li>▪ Cognitive reframing</li> </ul>	

<b>Parent Competency &amp; Learning Domain</b>	<b>Training Aims &amp; Motivation</b>	<b>Session and Content</b>	<b>Training methods &amp; equipment</b>	<b>Evaluation</b>
	child's established disability)	<ul style="list-style-type: none"> <li>- Explain transactional regulation theory simply (Sameroff &amp; Fiese, 2000), and how the child's environment (social, physical) can be controlled to promote the child's optimum functioning within the limits of the established disability</li> <li>- Parent is the most important person in the child's social environment, who can bring changes in the social and physical environment, by accessing help when you don't know how to solve difficult problems associated with your child's established disability (e.g. communication difficulties), or other problems that make it difficult to care for the child (e.g. lack of financial resources) – as already discussed by many parents on Day 1.</li> <li>- recognition of problems (communication and other) is the first important step.</li> </ul>		
<b>Perception of child's communication problem</b> - The ability to recognize that the child's communication skills are delayed or inappropriate when compared to peers his/her age in the community. The latter will reflect the parent's knowledge of typical communication development.	- To provide brief information on typical communication development in young children 0-6 years	- typical communication development in young children 0-6 years (Rossetti, 2001)	<ul style="list-style-type: none"> <li>▪ Brief lecture using power-point slides (5 minutes)</li> <li>▪ Communication Development Checklist (Shipley &amp; McAfee, 2009)</li> <li>▪ Group discussion and real-life application. Use handout to facilitate reference to own child's communication skills and challenges (15 minutes)</li> </ul>	

<b>Parent Competency &amp; Learning Domain</b>	<b>Training Aims &amp; Motivation</b>	<b>Session and Content</b>	<b>Training methods &amp; equipment</b>	<b>Evaluation</b>
<p><b>1.2 Problem attribution</b>            - awareness of the difference between initial and maintaining causes            - attribute the <i>initial cause</i> of the child's communication disability to factors (either environmental or personal) that were beyond the control of the parent.</p>	<p>- To discuss the significance of beliefs regarding causation and how it influences parent's positive coping and functioning. It also influences parents' communication of the problem to speech-language therapists ( to be discussed on Day 3).            - To discuss the importance of understanding the initial cause of the child's disability (established risk factor and associated communication disability), and the need to adopt a positive or facilitative orientation to problem attribution.</p> <p><b>Motivation:</b>            A facilitative/positive problem attribution style is critical to enable the parent to remain optimistic and utilize positive problem solving skills and pursue ECCI services (Peterson &amp; Steen, 2002; D'Zurilla &amp; Nezu, 1999).</p> <p>- To discuss the relevance of understanding the</p>	<p>- Discuss cultural beliefs about the causes of disability &amp; implications for positive coping and functioning            - Discuss positive/facilitative problem attributions as outlined by D'Zurilla &amp; Nezu (1999, 2010) and reviews of parents who coped positively in Appendix A. For example:</p> <ul style="list-style-type: none"> <li>• perceive the child's disability as an inevitable challenging life event that one must learn to cope with.</li> <li>• do not interpret the child's disability as a reflection of your failure. Do not blame yourself, it is not your fault.</li> <li>• accept and approach the challenge, rather than avoiding or denying. The latter are likely to result in negative outcomes for the child and family.</li> <li>• initiate help-seeking with confidence by making contact with ECCI services or approaching community clinics/hospitals for assistance.</li> </ul> <p>Briefly discuss key aspects of the</p>	<ul style="list-style-type: none"> <li>▪ Problem-solving group discussion and learner input. Identify how mothers in the group who are coping better, manage cultural beliefs.</li> <li>▪ Constructive Feedback</li> <li>▪ Cognitive re-framing</li> <li>▪ Power-point slides highlighting positive coping strategies of parents in Appendix A (15 minutes)</li> </ul>	<ul style="list-style-type: none"> <li>• Pre-and-Post Training Interview Schedule</li> <li>• Informal evaluations during training</li> <li>• Training session evaluation</li> </ul>

<b>Parent Competency &amp; Learning Domain</b>	<b>Training Aims &amp; Motivation</b>	<b>Session and Content</b>	<b>Training methods &amp; equipment</b>	<b>Evaluation</b>
<p>- attribute the <i>maintaining cause</i> of the child's communication disability to factors (either environmental or personal) that can be controlled by the parent or other significant individuals (eg. ECI professionals).</p>	<p>maintaining cause of the child's disability (established risk factor and associated communication disability) for effective and sustainable intervention planning.</p> <p><b>Motivation:</b> According to Rossetti (1996, p. 6) "assessment and management decisions should be made with a complete understanding of how causal factors interact and relate to a child's communication impairment." The transactional model provides the current framework for understanding causation, and emphasizes the reciprocal relationship between the child's environment and biologic constitution (Rossetti, 1996). Thus, even though the child presented with an established disability, it was still possible to modify personal and/or environmental factors to facilitate the child's</p>	<p>transactional model of causation (Rossetti, 1986, p. 6) and implications for the management of young children with communication disabilities</p>	<ul style="list-style-type: none"> <li>• Lecture using power-point slide</li> <li>• Guided reflection and problem-solving group discussion – encouraging parents to identify factors in their environments that could be modified during ECCI to promote family's positive functioning (15 minutes)</li> </ul>	

Parent Competency & Learning Domain	Training Aims & Motivation	Session and Content	Training methods & equipment	Evaluation
	communication development (for example, through the use of alternate and augmentative communication in the case of a child with limited or no functional speech).			
		<b>Tea break : 10.30-11.00am 30 minutes</b>		
		<b>Day 2 Session 2: 11.00am -12.45pm 105 minutes</b>		
<p><b>1.3 Personal Control</b>            Demonstrate the <b>beliefs</b> that:            - ECCI can ameliorate or remediate the child’s communication disability</p> <p>- parent is capable of assisting the child to reach his/her full developmental potential within the limits of the established disability, through the guidance of supportive ECCI professionals and family/friends</p>	<p>- To provide parent with information that illustrates the efficacy of ECI and ECCI, and the critical role that active parent involvement plays in this regard. Family-centered assessment and intervention is the recommended paradigm (Dunst &amp; Trivette, 1994; Dunst, 2004; Neely-Barnes &amp; Dia, 2008)</p> <p><b>Motivation</b>            According to D’Zurilla &amp; Nezu (1999) perceived control and self-efficacy expectations reduce anxiety and facilitate adaptive coping in stressful situations.            International and national legislation mandate the provision of ECI for young</p>	<p>Provide information on the efficacy of ECI and ECCI services (Rossetti, 2001; Dunst &amp; Trivette, 1994; Dunst, 2004; Neely-Barnes &amp; Dia, 2008). Illustrate benefits through a parent selected from a local ECCI program me, sharing her personal experiences. Mother typifies what a “warrior mum” is.</p>	<ul style="list-style-type: none"> <li>▪ Lecture using power-point slides (10 minutes)</li> <li>▪ Modeling and demonstration: video 1 of a confident parent sharing her positive experiences of ECCI and the benefits for her child with severe communication disabilities secondary to cerebral palsy. Parents’ decision to take an active role during intervention and its benefits for the parent and family, are also emphasized. See Appendix T for details of the video. (5 minutes)</li> <li>▪ Cognitive reframing</li> </ul>	<ul style="list-style-type: none"> <li>• Pre-and-Post Training Interview Schedule</li> <li>• Informal evaluations during training</li> <li>• Training session evaluation (Appendix V)</li> </ul>

Parent Competency & Learning Domain	Training Aims & Motivation	Session and Content	Training methods & equipment	Evaluation
	<p>children with disabilities based on efficacy studies (Rossetti, 2001; Integrated National Disability Strategy, 1997; NDP, 2011)</p> <p>- To discuss the significance of collaborative problem solving in facilitating the planning and implementation of effective and sustainable ECCI.</p> <p><b>Motivation</b>            Parents' confidence in their ability to assist their child reach his/her full developmental potential in all areas, including communication, is critical to facilitate progress during intervention. According to Rossetti (1996), the level of active parent involvement is an important factor that is linked to the efficacy of ECI. Active parent involvement enables the child to reach his/her full developmental potential, within the restrictions placed by the established risk factor (Rossetti, 2001). Assistance from supportive</p>	<p>The significance of active parent involvement in facilitating effective and sustainable ECCI (Rossetti, 2001; Alant, 2005; Neely-Barnes &amp; Dia, 2008)</p> <p>- The critical information that only parents can provide for planning effective and sustainable ECCI (e.g. the child's functioning in the family's daily routine, family and community resources, etc.).</p>		

Parent Competency & Learning Domain	Training Aims & Motivation	Session and Content	Training methods & equipment	Evaluation
	<p>informal (family and friends) and formal resources play an important role in providing an enabling context for the parent to develop this confidence (Dunst et al., 1994)</p>			
<p><b>1.4 Problem appraisal</b>            - a positive <b>attitude</b> toward parenting by appraising the child's communication disability as a "challenge" or situation that will bring positive benefits to themselves and the family</p>	<p>- To facilitate the parent's ability to positively appraise the child's established and communication disability as a challenge and opportunity for the family to learn and benefit from.  <b>Motivation:</b>            Parents who appraise their child's disability as a challenge or an opportunity that will bring benefits to themselves and the family are more likely to approach the problematic situation and initiate effortful, problem solving activity - for example, seeking ECCI for their child. On the other hand, parents who appraise the event as negative or threatening are more likely to be anxious or avoid the situation. The latter reactions do not facilitate the parent's positive</p>	<p>Provide information on:            - the significance of positive appraisal for facilitating positive functioning in the child, parent and family (Carvier &amp; Scheier, 2002; Dienstbier &amp; Zillig, 2002; D'Zurilla &amp; Nezu, 1999, 2010).            - Benefit finding and benefit reminding (Tennen &amp; Affleck, 2002) as a strategy for triggering positive appraisals. Use of a gratitude journal to document benefits and positive experiences of disability (see Appendix Q for details).</p>	<ul style="list-style-type: none"> <li>▪ Lecture using power-point slides</li> <li>▪ Cognitive reframing</li> <li>▪ Gratitude journal - introduce parents to the benefits</li> <li>▪ Demonstration through group discussion – share information from parents' experiences in Appendix A as a stimulus for parents to share their own experiences of finding benefits to parenting children with disabilities</li> <li>▪ Real life application. Homework assignment – parents to use the gratitude journal given to document two ways in which they have benefited from parenting their child</li> </ul>	<ul style="list-style-type: none"> <li>• Pre-and-Post Training Interview Schedule</li> <li>• Informal evaluations during training</li> <li>• Training session evaluation</li> </ul>

Parent Competency & Learning Domain	Training Aims & Motivation	Session and Content	Training methods & equipment	Evaluation
	functioning (D’Zurilla & Nezu, 1999, 2010; Carvier & Scheier, 2002)		with a disability. For discussion on Day 4. (30 minutes)	
<b>1.5 Time/Effort Commitment</b> - an <b>attitude</b> of willingness to devote the necessary time and effort to attend ECCI with the child and implement intervention activities at home , or make arrangements for a family member/ alternate caregiver to do so.	- To highlight the significance of parents’ commitment of time and effort to access resources to manage problems positively (i.e. child’s communication and other problems)  <b>Motivation:</b> As already stated, active parent involvement is an important factor that promotes the efficacy of ECCI (Rossetti, 1996; 2001). The parent’s recognition of the value of communication skills, the efficacy of ECCI, as well as an enabling intervention environment will encourage parents to commit time and effort and persist, despite challenging circumstances (D’Zurilla, 1986; D’Zurilla & Nezu, 1999; Dunst et al., 1994; Dunst, 2004)	The recommended practice of family -centered assessment and intervention (Dunst, 2004; Neely-Barnes & Dia, 2008), and the benefits of active parent involvement for effective and sustainable intervention planning and evaluation is covered in the content above.  The need for parents to make the commitment of time and effort will be stressed.	<ul style="list-style-type: none"> <li>• Demonstration and group discussion of parent video – highlight parents’ appraisal, personal control (outcome expectation and self-efficacy), and decision to commit time and effort to ECCI. All significant to achieving positive outcomes (10 minutes)</li> </ul>	<ul style="list-style-type: none"> <li>• Pre-and-Post Training Interview Schedule</li> <li>• Informal evaluations during training</li> </ul>
	- To consolidate training on adopting a positive problem solving mindset when facing child’s disability and	- Summary of key points on each of the problem orientation variables. Reinforce concept of the “warrior mum”.	▪ Handout – “Getting the help you need when talking to professionals”	

Parent Competency & Learning Domain	Training Aims & Motivation	Session and Content	Training methods & equipment	Evaluation
	<p>other challenging circumstances</p> <p>- Conclude session</p>	<p>- Illustrate how the key points can be applied to other stressful, challenging experiences.</p> <p>- Overview of positive coping strategies. Use the five coping resource framework (Folkman et al., 1979) to consider simple, inexpensive ways of promoting parents' health and energy, supportive social networks, positive beliefs about problems in general, disability, and self, accessing other resources (e.g. social grants, etc.). For example, exercise, eating healthy meals, meditation, listening to music, taking a bath, trusting and training family members/others as caregivers, developing supportive relationships with other parents who have children with disabilities, etc.</p> <p><b>12.45-1.00pm</b>          Provide motivational messages to facilitate parents' positive problem orientations. Parent evaluation of Day 2, lucky draw, give parents transport money &amp; gratitude journals.</p>	<p>(Appendix S) – (10minutes)</p> <ul style="list-style-type: none"> <li>▪ Presentation by a cancer survivor. Demonstrates use of the five principles in managing a life-threatening illness. Encourages parents to place their challenges in perspective, when compared to those confronted by others (5 minutes)</li> <li>• Group discussion &amp; consolidation (25 minutes)</li> <li>• Learning exercise using power-point motivational slide-show "We are like pencils" (see Appendix Q for content overview) (10 minutes)</li> <li>• Handout with three motivational messages</li> <li>• Training session evaluation sheet, transport money, gratitude journal,</li> </ul>	

Parent Competency & Learning Domain	Training Aims & Motivation	Session and Content	Training methods & equipment	Evaluation
			lucky draw pamper-packs	
		<b>Day 3 Session 1: 9.00a.m-10.30am 90 minutes</b>		
	<b>Introduction to Day 3</b> - To summarize the training of Day 1 & 2; discuss parents' evaluation of training on Day 2 and make any changes required; check on parents' progress with writing in their gratitude journals and provide support if required. - To identify the training goals for Day 3	- Key learning points of Day 2 are summarized, namely, key principles that facilitate parents' positive orientations to problems experienced.  - The main focus of Day 3 is to enhance parents' knowledge of, and skills in describing their problems and needs effectively when communicating with speech-language therapists during ECCI.	<ul style="list-style-type: none"> <li>• Discussion (5 minutes)</li> </ul>	<ul style="list-style-type: none"> <li>• Pre-and-Post Training Interview Schedule</li> <li>• Informal evaluations during training</li> <li>• Training session evaluation form</li> <li>• General evaluation questionnaire</li> </ul>
<b>DV2: Problem Definition</b> <b>Parent will demonstrate the following:</b> 2.1 Skill in communicating information about the problem and need in an organized way according to the three components, namely: a). what is the problem, to whom is it a problem and why?	- To facilitate parent's ability to communicate problems experienced in parenting their child with a disability, according to the three components listed.  <b>Motivation:</b> Parents must be able to order their thoughts in a clear chronology so that the	- The importance of presenting information in an organized format to enable the professional to obtain a coherent understanding of the problem and need. Implication for planning effective, sustainable interventions, and ensuring that parent receives the help needed. - Outline of the three components	<ul style="list-style-type: none"> <li>• Lecture using power-point slides (15 min)</li> <li>• Handout – "Getting the help you need when talking to professionals" (Appendix S) (10 minutes)</li> <li>• Simulation: Videos 2 and 3 of parents describing their</li> </ul>	<ul style="list-style-type: none"> <li>• Pre-and-Post Training Interview Schedule</li> <li>• Informal evaluations during training</li> <li>• Training session evaluation form</li> </ul>

<b>Parent Competency &amp; Learning Domain</b>	<b>Training Aims &amp; Motivation</b>	<b>Session and Content</b>	<b>Training methods &amp; equipment</b>	<b>Evaluation</b>
<p>b) what changes / additions are desired, to whom and why.            c) what obstacles prevent the development of desired communication behaviours and/or attainment of desired resources</p>	<p>therapist is able to understand the problem &amp; need (Fiese &amp; Sameroff, 1999). An organized description clearly orientates the listener to the context and referents (who, what, where, when and why) and is a key component to a coherent narrative (Fiese &amp; Sameroff, 1999). The three components outlined by D’Zurilla (1986) and D’Zurilla &amp; Nezu (1999) provide a coherent structure that facilitates the therapist’s understanding of the problematic situation</p>		<p>parenting problems and needs to a SLT (Appendix T) – focus on how information is organized versus disorganized in each (10 minutes)</p> <ul style="list-style-type: none"> <li>• Group discussion evaluating videos, using the guidelines provided in the handout. (20 minutes)</li> <li>• Role playing help-seeking in ECCI. Parent to describe their problems (child’s communication and/or other problems) and needs to the speech-language therapist to access ECCI. Parents grouped in pairs. Each to take turns in the roles of speech-language therapist and parent. To use the handout to communicate and evaluate descriptions of problems and needs. (30 minutes)</li> </ul>	<ul style="list-style-type: none"> <li>• General evaluation questionnaire</li> </ul>
		<p><b>Tea-break: 10.30am-11.00am</b></p>	<p><b>30 minutes</b></p>	

Parent Competency & Learning Domain	Training Aims & Motivation	Session and Content	Training methods & equipment	Evaluation
<p>2.2 Skill in providing relevant factual and perceptual information that is important for the therapist to understand the problem, and plan effective, sustainable intervention.</p>	<p>To facilitate parent’s ability to provide relevant descriptions that are:</p> <ul style="list-style-type: none"> <li>- specific to the child’s communication problem and/or other associated problems</li> <li>- explained using concrete/operational terms by providing examples from the child and family’s daily context</li> <li>- comprehensive (i.e. provides a historical context from onset to current functioning)</li> </ul> <p><b>Motivation</b>            D’Zurilla (1986) and D’Zurilla &amp; Nezu (1999) indicate that it is important for problem solvers to know the kinds of information to look for and what cues to pay attention to, when gathering information about a problem and presenting it to help-givers. Task and socio-behavioural information have been identified as relevant for understanding a problem</p>	<p><b>Day 3 Session 2: 11.00am-12.45pm 105 minutes</b></p> <ul style="list-style-type: none"> <li>- Parents’ knowledge of the role of the speech-language therapist is important to ensure that they provide information that is appropriate for the specific help that they need (Woods &amp; Lindeman, 2008). Provide information about the role of the speech-language therapist, in relation to other professionals, specifically, physiotherapist, occupational therapist, and social worker.</li> <li>- Task information refers to the various tasks that parents engage in during parenting (e.g. bathing, feeding, etc.), and socio-behavioural information refers to the parent’s beliefs, values, goals and feelings about the role of parents, child development, disability and communication disability in particular. In order to facilitate the therapist’s understanding of the problem, parents must be able to provide both types of information, which are specific to the child’s communication disability, and/or associated conditions that impinge on the disability.</li> <li>- The information must contain facts and parents’ perceptions, and must be described as it occurs within the family’s daily context - to facilitate assessment and intervention planning.</li> <li>- information in each of the three components must be comprehensive to enable the therapist to develop a full understanding of the problematic situation.</li> </ul>	<ul style="list-style-type: none"> <li>• Lecture using power-point slides (15 minutes)</li> <li>• Lecture using power-point slides on the role of the speech-language therapist &amp; other professionals listed (Rosserti, 2001).</li> <li>• Handout– “Getting the help you need when talking to professionals” (Appendix S) (10 minutes)</li> <li>• Demonstration using videos 2 and 3 (Appendix T) of parents describing their parenting problems – this time the focus is on how parents provide relevant versus irrelevant information in each. (20 minutes)</li> <li>• Group discussion evaluating videos and its impact on effective and sustainable intervention planning. The guidelines</li> </ul>	<ul style="list-style-type: none"> <li>• Pre-and-Post Training Interview Schedule</li> <li>• Informal evaluations during training</li> <li>• Training session evaluation form</li> <li>• General evaluation questionnaire</li> </ul>

Parent Competency & Learning Domain	Training Aims & Motivation	Session and Content	Training methods & equipment	Evaluation
	(both are discussed in Section 2.3.2.2).		provided in the handout will be used to guide evaluation (20 minutes) <ul style="list-style-type: none"> <li>• Role-playing – as described above (30 minutes)</li> </ul>	
	To consolidate information regarding desired problem definition skills	Summary of information for 2.1 and 2.2	<ul style="list-style-type: none"> <li>• Handout - “Getting the help you need when talking to professionals”</li> <li>• Application to real life. Homework assignment: parents to follow handout guidelines and document their descriptions of parenting problems and needs. For discussion on Day 4.</li> </ul>	
	- Conclude session	<b>12.45-1.00pm</b> - Parents to bring a photo of their child to share with the group, and gratitude journal (homework given on Day 2). - Parent evaluation of Day 3, lucky draw, give parents transport money & gift for child	<ul style="list-style-type: none"> <li>• Training session evaluation forms, transport money, gift (pencil case), lucky draw pamper-packs</li> </ul>	
Parent will demonstrate positive problem solving orientations, and skills	<b>Introduction to Day 4</b> - To summarize the training of Days 1-3; discuss parents’ evaluation of	<b>Day 4: Sessions 1 90 minutes</b>	<ul style="list-style-type: none"> <li>• Discussion using Handout - “Getting the help you need when</li> </ul>	<ul style="list-style-type: none"> <li>• Pre-and-Post Training Interview Schedule</li> </ul>
		- Key learning points of Days 1-3 are summarized, namely, key principles that facilitate parents’ positive orientation to and definition of problems experienced in parenting children with moderate to		

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<p>in organizing and providing relevant information when defining problems to professionals during ECCI.</p>	<p>training on Day 3 and make any changes required. required.            - To identify the training goals for Day 4</p>	<p>severe communication disabilities, secondary to established disabilities.</p> <p>- The main focus of Day 4 is to strengthen parents' attitude toward, knowledge of, and skills in help seeking when approaching and communicating their problems and needs to professionals (specifically speech-language therapists) during ECCI.</p>	<p>talking to professionals” (10 minutes)</p>	<ul style="list-style-type: none"> <li>• Informal evaluations during training</li> <li>• Training session evaluation form (Appendix V)</li> <li>• General evaluation questionnaire (Appendix W)</li> </ul>
	<p>- To review homework assignment given on Day 2, that is, parents' gratitude journal entries            - To facilitate parents' positive perceptions of the child with a disability as just another member of the family (Turnbull et al., 1993; Maul &amp; Singer, 2009), and strengthen skills in introducing the child to other people. For example, family, friends, professionals, etc.  <b>Motivation:</b> The above was identified as a stressful event for most parents during the pre-training interviews, reflecting low levels of appraisal and personal control. Research on families who function</p>	<p>- Brief overview of the benefits of keeping a gratitude journal, with the main reason being that it is a tool for strengthening parents' positive appraisals of parenting children with disabilities or any other challenges experienced (Dienstbier &amp; Zillig, 2002).            - Guidelines on “introducing my child to others”. Parents encouraged to place greater emphasis on issues such as the child's personality, strengths and hobbies, as they would when they introduced any other child in the family to others. To also include a brief description of the disability and the restrictions it imposes on the child, for example, communication, motor, cognitive functioning etc. (Turnbull et al., 1993; Maul &amp; Singer, 2009). Parents' communication must reflect their positive appraisal of disability, and personal control (i.e. positive self-efficacy and outcome expectancy).</p>	<ul style="list-style-type: none"> <li>• Problem-solving group discussion to identify relevant guidelines for parents to introduce the child with disability to other people (Woods &amp; Lindeman, 2008). Guidelines documented on power-point slide.</li> <li>• Handout - “Getting the help you need when talking to professionals”</li> <li>• Photos of children</li> <li>• Individual practice. Parent presentations on entries from gratitude journal, and introducing their child to the group. Each parent allocated five</li> </ul>	

Parent Competency & Learning Domain	Training Aims & Motivation	Session and Content	Training methods & equipment	Evaluation
	<p>positively highlight the emphasis placed on treating the child with a disability as another member of the family (Maul &amp; Singer, 2009).</p>		<p>minutes to do both. Trainer provides supportive comments using problem orientation guidelines from the handout and power-point slide for parents' introductions. Parents are encouraged to do the same, to provide feedback to the parent presenter. (75 minutes: 5 minutes per parent)</p>	
		<p><b>Tea-break: 10.30-11.00am 30 minutes</b></p>		
		<p><b>Day 4 Session 2: 11.00am-12.45pm 105 minutes</b></p>		
	<p>- To review homework assignment given on Day 3, that is, parents' communication of problems and needs to speech-language therapist</p>	<p>- Key principles of effective communication of problems and needs are reiterated very briefly, using the handout. - Guidelines on providing supportive and constructive feedback to parents (Dunst &amp; Trivette, 2009)</p>	<ul style="list-style-type: none"> <li>• Handout - "Getting the help you need when talking to professionals"</li> <li>• Individual practice presentations to the group. Group to evaluate presentations and provide supportive and constructive feedback.</li> <li>• Research assistant documents feedback (strengths and weaknesses) on a</li> </ul>	

Parent Competency & Learning Domain	Training Aims & Motivation	Session and Content	Training methods & equipment	Evaluation
			separate sheet for each parent. Parents encouraged to use feedback to improve their problem definition skills (75 minutes: 5 minutes per parent)	
	- To manage parents' questions and/or any queries that they may have regarding the training.	Open session to manage any queries that parents may have. Use this time to consolidate parents' understanding of problem orientation and problem definition during ECCL. The concepts of parent as decision-maker, change-agent and "warrior mum" are reinforced.	<ul style="list-style-type: none"> <li>• Problem-solving group discussion (25 minutes)</li> <li>• Power-point slideshow "Absolutely fantastic slideshow" – promotes positive orientation to problems (see Appendix T for content overview) (5 minutes)</li> </ul>	
	- Conclude training programme	<b>12.45-1.00pm – 15 minutes</b> - Parent evaluation of Day 4 and overall evaluation of pre-training interviews and training programme, lucky draw - Parents' given certificates for attending the four-day training programme - Parents thanked for participating in the training and informed that resident speech-language therapists at the hospitals will be informed about the training so that training outcomes are maintained.	<ul style="list-style-type: none"> <li>• Training session evaluation format (Appendix V)</li> <li>• General evaluation questionnaire (Appendix W)</li> <li>• Certificate of attendance (Appendix X)</li> <li>• Lucky draw pamper-packs</li> </ul>	<ul style="list-style-type: none"> <li>• Training session evaluation (Appendix V)</li> <li>• General evaluation of training programme (Appendix W), and pre-training interviews</li> </ul>

Parent Competency & Learning Domain	Training Aims & Motivation	Session and Content	Training methods & equipment	Evaluation
		- Conclude with final set of lucky draws, thereby ensuring that every parent who attended received a sponsored gift pack.		
<p><b>Phase 3</b>            To <i>maintain</i> attitude and behaviour changes in parents' problem orientations and problem definition in the form of follow-up services.  <b>Motivation</b>            A systems-based/ecological approach to intervention is critical to ensure that changes made to parents' attitudes towards problems and skills in problem definition are maintained, and if relapses do occur, systems are in place to assist the parent in using the preferred competencies (Schwarzer, 1999; 2001; Nelson, Prilleltensky &amp; MacGillivray, 2001).</p>				
Parent will demonstrate positive problem solving orientations, and skills in organizing and providing relevant information when defining problems to professionals during ECCI.	To commence the attitude and behaviour maintenance process by providing parents with short homework assignments after each session during the training period.	- The significance of homework assignments in promoting parents use of the targeted problem solving attitudes and skills - the content of the assignments were drawn from the parents experiences in roles carried out in their daily context – thus ensuring that they were socially valid (Dunst & Trivette, 2009; Saunders et al., 2009).	<ul style="list-style-type: none"> <li>• Short home assignments after each session – targeting specific attitudes and skills learnt during the session.</li> </ul>	<ul style="list-style-type: none"> <li>• Discussion and Constructive feedback (e.g. story of warrior mum)</li> <li>• Individual presentation and constructive feedback (e.g. problem definition)</li> </ul>
	To ensure that parents had easy access to the trainer during the course of the training period, and after – should the need arise.	Provide the trainer's contact details (telephone, email address)	<ul style="list-style-type: none"> <li>• Information included in the handout</li> </ul>	
	To set up follow-up services with speech-language therapists working in the clinic and hospital contexts where parents receive ECCI	Provide information on: - The need for positive functioning in parents of children with disabilities	<ul style="list-style-type: none"> <li>• Information sharing and training session to be incorporated into a monthly meeting of the Kwa-Zulu Natal</li> </ul>	<ul style="list-style-type: none"> <li>• Bi-monthly monitoring of participant parents' problem solving attitude</li> </ul>

Parent Competency & Learning Domain	Training Aims & Motivation	Session and Content	Training methods & equipment	Evaluation
	<p>services. The necessary information and skills will be provided <i>after</i> the completion of this study, to ensure that they are able to monitor, strengthen and assist parents during ongoing intervention.</p>	<ul style="list-style-type: none"> <li>- the critical roles played by parent's orientations to problems and definitions of problems when accessing ECCI</li> <li>- Guidelines for facilitating positive problem orientations</li> <li>- Guidelines for enabling parents to provide organized and relevant information during problem definition</li> <li>- Guidelines for monitoring and strengthening parents' orientations to problems and problem definition skills during ECCI</li> </ul>	<p>Department of Health Speech-Language Therapy and Audiology Forum.</p> <ul style="list-style-type: none"> <li>• Handout: Getting the help you need when talking to professionals</li> <li>• Trainer to provide ongoing support</li> </ul>	<p>and behaviour maintenance through email correspondence with SLTs for 6 months after training</p>
<p><b>Phase 4</b> To evaluate the design and implementation of the training programme</p> <p><b>Motivation</b> Quality training programmes need to be evaluated for the following four reasons: (i) to determine its' effectiveness in facilitating parents' positive orientation to problems, and skills in problem definition; (ii) to determine the extent to which it met the parents ' needs that were identified in the focus group, (iii) to obtain support for programme expansion in supporting parents receiving ECCI in hospital and clinic contexts in Kwa-Zulu Natal, particularly participants who were not part of the study sample, and finally (iv) to identify factors both internal and external to the training programme that facilitated or inhibited its impact, for planning future training initiatives in similar contexts (Saunders et al., 2009). Forgatch et al., (2005) utilize the term 'fidelity' to focus specifically on the trainer's <i>adherence</i> to the intervention's core content components and competent execution using evidence-based clinical and teaching practices. The trainer's adherence to the training plan and competent execution of training is significantly related to treatment outcome.</p>				
	<p>To determine the trainer's <i>adherence</i> to the intervention's core content components and <i>competent execution</i> of clinical and teaching practices during training</p>	<p><b>Method:</b> Two independent raters, who were familiar with the programme's underlying theory, content and training processes, were selected to view the training programme video recordings and rate the trainer's adherence to and competent execution of the training plan. <b>Training:</b> Guidelines provided by Forgatch et al. (2005) were used to guide the process. Raters were trained using the pilot study recordings of the training programme. They were required to</p>	<ul style="list-style-type: none"> <li>▪ Integrity of training programme rating sheet (Appendix Y)</li> <li>▪ Detailed Training Plan (Appendix U)</li> <li>▪ Video-recordings of the training programme (four days and eight training sessions)</li> </ul>	<ul style="list-style-type: none"> <li>▪ Two independent raters evaluated the fidelity of the training programme</li> </ul>

Parent Competency & Learning Domain	Training Aims & Motivation	Session and Content	Training methods & equipment	Evaluation
		<p>familiarize themselves with the coding sheet, view and rate the 4 hour video-tape and discuss disagreements. At the conclusion of an 8 hour training session, raters obtained 80% inter-rater agreement, which was deemed sufficient in view of the 70% reliability criterion set by Forgatch et al. (2005).</p> <p>For the main study, raters were required to randomly select 50% of each of the four days' training sessions for rating. The raters watched the video-recordings together, but scoring was done independently.</p>	<ul style="list-style-type: none"> <li>▪ Recording of video on a CD, for viewing on the laptop</li> <li>▪ 2 x pens</li> </ul>	
	To determine the effectiveness of the training programme in facilitating parents' acquisition of positive orientations to problems, and skills in problem definition	Analysis and comparison of pre-training and post-training interviews.		<ul style="list-style-type: none"> <li>▪ Pre-and-Post Interview Schedule</li> </ul>
	To determine the extent to which the training programme met the needs that parents identified in the focus group,	Analysis of pre-and-post training interviews and parents' evaluation of the overall training programme.		<ul style="list-style-type: none"> <li>▪ Pre-and-post Interview Schedule</li> <li>▪ General Evaluation Questionnaire (Appendix W)</li> </ul>
	To identify factors both internal and external to the training programme that facilitated or inhibited its impact, for the planning of future training initiatives in similar contexts	Day1-4: Training session evaluation s Day 4 Session 2: General evaluation of the entire training programme and pre-training interviews		<ul style="list-style-type: none"> <li>▪ General Evaluation Questionnaire (Appendix W)</li> <li>▪ Training session Evaluation Form (Appendix V)</li> </ul>

## Appendix V

### Training Session Evaluation Form

Thank you for participating in this training programme. Please comment on the training that you received today.

The statements below look at different aspects of the training. Please read each statement and place an X to show if you agree, disagree or are unsure about it.

Participant number				V1	<input type="checkbox"/>
	<b>Agree 1</b>	<b>Unsure 2</b>	<b>Disagree 3</b>		
The trainer was well prepared for the training				V2	<input type="checkbox"/>
The training was easy to follow				V3	<input type="checkbox"/>
I feel comfortable participating in the different training methods, for example, role play; group discussions				V4	<input type="checkbox"/>
The length of the training was sufficient				V5	<input type="checkbox"/>
The videos and slideshows help me to learn better ways of managing my difficulties				V6	<input type="checkbox"/>
There were enough opportunities for me to participate during training				V7	<input type="checkbox"/>
I will be able to work on the homework assignments given				V8	<input type="checkbox"/>

#### 2. Overall rating of training

(mark with an X)

1	2	3	4	5		V9	<input type="checkbox"/>
very poor	poor	satisfactory	good	Very good			

#### 3. Suggestions to improve training

V10

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*Thank you for taking the time to complete this form.*

**Legini Moodley**

## Appendix W

### General evaluation questionnaire

**Instruction:** Thank you very much for participating in the study. Please share your thoughts on the following questions. Your honest feedback is very important as it will help in planning future training programmes for parents.

Participant number	V1 <input style="width: 40px; height: 20px;" type="text"/>
--------------------	--

1. How useful did you find the information given during this training?  
 Place a cross (X) in the appropriate box.

<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>		
Very useful	Useful	Only a bit useful	Not at all useful		V2 <input style="width: 40px; height: 20px;" type="text"/>

2. The statements below describe the training. Please read each statement and place an X to show if you **agree**, **disagree** or are **unsure** about it.

	Strongly Agree <b>1</b>	Agree <b>2</b>	Unsure <b>3</b>	Disagree <b>4</b>	
The training helped me strengthen or develop a positive attitude toward parenting my child					V3 <input style="width: 40px; height: 20px;" type="text"/>
The training helped me to describe my child's communication problems better when I ask for help from the speech therapist					V4 <input style="width: 40px; height: 20px;" type="text"/>
The training helps me to describe any problem better when I ask for help from anyone					V5 <input style="width: 40px; height: 20px;" type="text"/>
I would recommend this training to other mothers who have a child with a communication or any other disability					V6 <input style="width: 40px; height: 20px;" type="text"/>

3. Which of the following made it **easy** or **difficult** for you to participate in the interviews and training?

For each statement, place a cross (X) in the appropriate column. If you have any additional comments, please write it in the section provided.

	Easy to participate <b>1</b>	Difficult to participate <b>2</b>	Additional Comments	
<b>Interviews</b>				
transport costs paid for by researcher				V7 <input style="width: 40px; height: 20px;" type="text"/>
Interviews conducted at home				V8 <input style="width: 40px; height: 20px;" type="text"/>
Interviews conducted at the hospital				V9 <input style="width: 40px; height: 20px;" type="text"/>
Getting help with child care				V10 <input style="width: 40px; height: 20px;" type="text"/>
The type of questions asked: e.g. easy to understand difficult to understand				V11 <input style="width: 40px; height: 20px;" type="text"/>
The interviewer e.g. easy to talk to				V12 <input style="width: 40px; height: 20px;" type="text"/>

	<i>Easy to participate</i> <b>1</b>	<i>Difficult to participate</i> <b>2</b>	<b>Additional Comments</b>	
difficult to talk to				
Anything else – please specify				V13
<b>Training programme</b>				
Information provided e.g. Relevant (easy) Irrelevant (difficult)				V14
The programme e.g. Fun and interesting (easy) Boring (difficult)				V15
The teaching methods e.g Interesting (easy) Boring (difficult)				V16
State which of the following training methods were easy or difficult:				
Role playing				V17
Group discussions				V18
Videos				V19
Slideshows				V20
Homework assignments				V21
Case studies/presentations				V22
Instructions				V23
The venue				V24
Tea and light lunches				V25
Number of training sessions				V26
Other – please specify				V27

4. Please suggest ways in which the study could have been planned better for you.

5. Do you have any other comments about the study?

*Thank you for taking the time to complete this questionnaire.  
Legini Moodley*



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UNIVERSITY OF PRETORIA  
YUNIBESITHI YA PRETORIA



Appendix X  
Certificate of attendance

Faculty of Humanities

**UNIVERSITY OF PRETORIA**  
**The Centre for Augmentative and Alternative Communication**  
**(CAAC)**



University of Pretoria

***Certificate of Attendance***

*I hereby certify that*

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*Attended the following 16 hour training programme:*

**Getting the help you need when talking to professionals:  
*A simple 2-step plan for parents***

Presented by

**Legini Moodley**

**At the Phoenix Assessment and Therapy Centre  
From 11-14 May 2009**

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**Legini Moodley**  
**Presenter**

**Date: May 2009**

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**Professor Juan Bornman**  
**Director: CAAC**

## Appendix Y

### Integrity of training programme rating form

*(Adapted from Forgatch, Patterson & DeGarmo, 2005)*

Thank you for reviewing the training programme. Please rate the training session according to the statements below.

Place an X in the appropriate column.

	1 Poor	2 Below satisfactory	3 Satisfactory	4 Good	5 Very good		
<b>Trainer's knowledge</b>						V1	
Demonstrates knowledge and understanding of the concept of problem orientation (DV1)							
Demonstrates knowledge and understanding of the concept of problem definition (DV2)						V2	
<b>Structure of training</b>							
Followed training plan with respect to content areas						V3	
Maintained orderly flow of information						V4	
Flexible and responsive to parents' needs without compromising training goals						V5	
Sensitive timing and pacing of content						V6	
Accomplished training session goals						V7	
<b>Teaching skills</b>							
Provided relevant information on the constructs of problem orientation and definition in an easy to understand format						V8	
Explained reasons for recommended behaviour changes (rationale)						V9	
Proficiency in using interactive teaching strategies and tools to facilitate parents' mastery and independent use of problem orientation and definition behaviours (eg role-plays, asking questions to elicit solutions, brainstorming, prompting, etc.)						V10	
<b>Clinical skills</b>							
Created a safe and supportive context for learning (supportive questioning style to facilitate open sharing of information, encouraging skill development, showing respect and value for parents, facilitating equal partnership, encouraging collaborative decision-making, etc.)						V11	
<b>(ii) Participants</b>							
<b>Adherence and participation during training</b>							
Participated actively in the essential components of the training plan, as directed by the trainer						V12	

	1 Poor	2 Below satisfactory	3 Satisfactory	4 Good	5 Very good	
Completed all homework assignment						V13 <input type="checkbox"/>
Showed interest in the training content						V14 <input type="checkbox"/>
Attended training session						V15 <input type="checkbox"/>

**2. Suggestions to improve training**

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*Thank you for taking the time to complete this form.*  
**Legini Moodley**

**Appendix Z**  
**Review of congruence between treatment and problem orientation questionnaire  
 and problem definition question**  
*(Adapted from Bagnato, Neisworth & Munson, 1997)*

Use the following scale to rate how well the two questionnaires guide the development of a useful and worthwhile training programme for promoting parents' positive orientations and definitions of problems experienced in parenting young children with moderate to severe communication disabilities.

**Instruction:**

*For each questionnaire, circle the rating that you think best describes each statement:*

**1 = poor      2 = somewhat poor      3 = somewhat good      4 = good**

<b>Dimensions of treatment and social validity</b>	<b>Problem orientation Questionnaire</b>				<b>Problem definition Questionnaire</b>			
Identifies training objectives	1	2	3	4	1	2	3	4
Objectives identified are relevant / useful to parent	1	2	3	4	1	2	3	4
Identifies training materials (content)	1	2	3	4	1	2	3	4
Training materials (content) are relevant for parent	1	2	3	4	1	2	3	4
Will detect progress/ changes in parents skills and perceptions after training	1	2	3	4	1	2	3	4
Assessment findings are socially relevant for the parent	1	2	3	4	1	2	3	4

## Appendix AA

### Detailed objectives, results and recommendations of pilot study 4

**Table Z1: Objectives, results and recommendations of pilot study 4**

Objectives	Materials and Equipment	Procedures	Results	Recommendations
<i>With respect to the pre-and-post training interview schedules</i>				
1. To determine the clarity of the information given to participants to explain the purpose of the study and the need for their participation, prior to collecting any data.	Information to the participant to obtain informed consent (Appendix AF)	During the pre-training interview the researcher read the explanation to the participant.	Participants found the explanation adequate. No further explanations were requested.	<b>No modifications were required.</b>
2. To determine the clarity and preciseness of the instructions given before completion of the pre-and-post : <ul style="list-style-type: none"> <li>- Biographical Information Questionnaire</li> <li>- Problem Orientation Questionnaire</li> <li>- Problem Definition Question</li> </ul>	1. Biographical Information Questionnaire (Appendix O)  2. Problem Orientation Questionnaire (Appendix J)  3. Problem Definition Question (Appendix K – question only)	Instructions for each section were read before data were collected.	Participants found the instructions clear. No questions were asked during the pre-and-post training interviews.	<b>No modifications were required.</b>

Objectives	Materials and Equipment	Procedures	Results	Recommendations
<p>3.1 To determine the ability of participants to understand all questions and provide the information required in the Biographical Information Questionnaire before and after training.</p> <p>3.2 To assess the ease with which the researcher could record data onto the Biographical Information Sheet</p>	<p>Biographical Information Questionnaire (Appendix O)</p>	<p>3.1 The researcher requested the required information with regard to 12 questions. During the post-training interview, the main headings were read out aloud and parents were requested to only provide information that had changed from that given in the pre-training interview.</p> <p>3.2 The researcher evaluated the data recording process.</p>	<p>3.1 All participants were able to understand the questions and provide the information required before and after training.</p> <p>3.2 The recording process was generally good, with only one problem noted in the pre-test. In Part 3, a section for capturing the child's date of birth was not included. The latter information is important to verify the child's age as given by the participant.</p>	<p><b>3.1 No modifications were required.</b></p> <p><b>3.2 A section for recording the child's date of birth was included for the post-test.</b></p>
<p>4.1 To determine the ability of participants to understand all questions and terminology used, as well as their ability to select their responses from the options provided in the Problem Orientation Questionnaire</p>	<p>4.1 Problem Orientation Questionnaire (Appendix J)</p>	<p>4.1 Video and audio-recordings commenced as soon as the researcher was ready to read the statements and response options. A copy of the questionnaire was enlarged (to size 14 font) to show participants the different response options that they could select from.</p>	<p>4.1 Participants were able to understand all questions and terminology used. Response options provided were appropriate, except for question B2, where the majority of the participants' responded with the statement: "I'm not sure". This was not included in the list of response- options provided for the pretest.</p>	<p><b>4.1 The response option "I'm not sure" was included for question B2. The response options were kept to a four-point scale by combining the second and third response options as follows: "A problem in the parent or the child". The previous options were:</b></p> <p><b>2: A problem in the parent</b></p> <p><b>3: a problem in the child</b></p> <p><b>The above modifications were made for the post-test.</b></p>
<p>4.2 . To assess the ease with which the researcher could record data onto the</p>	<p>4.2 Problem Orientation Questionnaire</p>	<p>4.2 The researcher circled the response options selected by participants.</p>	<p>4.2 No problems were encountered in capturing participants' responses during the pre-and-post training interviews.</p>	

Objectives	Materials and Equipment	Procedures	Results	Recommendations
Problem Orientation Questionnaire.	(Appendix J)			<b>4.2 No modifications were required.</b>
5. To determine the time taken to complete the entire interview including: explanations to the participants and the three sections of the interview schedule.	Stopwatch The interview process was planned to take not more than 1 hour of the participants' time, to encourage their participation in the pre- and post-training sessions.	The interview process was timed from the beginning to end during the pre-and-post training interviews..	The entire <i>pre-training</i> interview took between 45-60 minutes to complete, whilst the <i>post-training</i> interview took between 15-20 minutes. An important finding that decreased the post-training time and improved the overall flow of information provided by participants, was the <i>sequence</i> in which the Problem Orientation Questionnaire and Problem Definition Question were implemented. The pre-training commenced with the Problem Orientation Questionnaire immediately after the Biographical Information Questionnaire, which resulted in participants' repeating some of the information (for example, perception of the cause of the problem) required for the Problem Definition Question. In addition, participants began to describe events during the problem orientation task – which were not required. However, more importantly, during the problem definition tasks, participants did not go into detail in describing aspects already discussed – which would result in them obtaining a lower rating. The latter, however, would then not reflect the real situation. Consequently, the sequence was changed for participant 2 in the pre-test and the 2 participants in the post-test to: Biographical Information; Problem Definition Question; Problem Orientation	<b>For the main study, modify the sequence of the interview schedule as follows:</b> <b>1. Information to participants to obtain informed consent</b> <b>2. Biographical Information Questionnaire</b> <b>3. Problem Definition Question</b> <b>3. Problem Orientation Questionnaire.</b>

Objectives	Materials and Equipment	Procedures	Results	Recommendations
6. To assess the suitability of the environments in which the pre-and-post training interviews occurred, to ensure that good quality video and audio- recordings were possible.	<ul style="list-style-type: none"> <li>- Interview environments had to be convenient for participants and were thus selected by the parents</li> <li>- Video and audio-recordings:               <ul style="list-style-type: none"> <li>▪ Sony DCR-HC28E video recorder</li> <li>▪ Video cassettes for recording interviews</li> <li>▪ Sanyo voice activated recording system (tape-recorder)</li> <li>▪ TDK 90 minute audio-recording cassette (60 minutes of tape)</li> </ul> </li> </ul>	The interview environments and audio-recordings were closely monitored for noise and distractions that would impact negatively on the transcription process.	<p>Questionnaire. The latter led to a better flow of information and provided a better reflection of the parent's skills in problem definition. In addition, participants' responses on the problem definition task also served to verify parents' responses on the problem orientation task.</p> <p>Both participants selected their home environments for both pre-and post-training interviews. Minor distractions were noted during the interview process. For example, interruptions by the child or other siblings. However, it was difficult for most participants to control these events as they were the only caregiver available at the time. During interruptions, the interview was terminated to allow the participant to respond to the children. The overall impact on the video and audio-recordings was minimal.</p>	<p><b>For the main study, recommend in advance, that where possible parents make arrangements to have another adult present in the home to take care of their children's needs during the one hour interview process. Explain the reason for this recommendation.</b></p>
To evaluate the ease with which the internal and external raters coped with the pre- and post-training rating/scoring process (following a training session).	<ul style="list-style-type: none"> <li>- Video and audio-recordings of the two participants' interviews</li> <li>- Transcript of the two interviews</li> </ul> <p>Procedural consistency:</p>	<p>Participants' video-recordings and audio-recordings with the transcripts were allocated to raters to evaluate which method was easier for raters to use to assess both procedural and measurement consistency.</p> <p>Procedural consistency</p>	<p>Procedural consistency:          Rater 1 experienced no problems in rating procedural consistency in the two interviews and data capture. Findings showed 100% consistency.</p> <p>Measurement consistency:          - The external raters recorded 1.5 hours for rating the 2 pre-training interviews</p>	<p><b>Evaluation of procedural consistency:          No modifications required for the main study.          Evaluation of measurement consistency:</b></p>

Objectives	Materials and Equipment	Procedures	Results	Recommendations
<p>(Note: Brief outline of the Rater Training Session:</p> <ul style="list-style-type: none"> <li>- Introduction to the aim and objectives of the study</li> <li>- Description of the three parts of the interview schedule and the underlying concepts</li> <li>- Description and discussion of the scoring system by utilizing examples that illustrate the three components of problem definition (i.e. what is the problem/ desired outcome/obstacles preventing desired outcome). Scripts of good and poor problem definition were used (Appendix T).</li> <li>- Raters were encouraged to contact the researcher immediately when difficulties were encountered. The researcher's contact details were provided)</li> </ul>	<ul style="list-style-type: none"> <li>- Rating form for procedural consistency in the interviews and data capture (Appendix AB)</li> <li>- Biographical Information Questionnaire (Appendix O)</li> <li>- Problem Orientation Questionnaire (Appendix J)</li> <li>- Problem Definition Question (Appendix K)</li> <li>Measurement consistency:               <ul style="list-style-type: none"> <li>- Problem Orientation Questionnaire (question B1 &amp; B4 transcribed) (Appendix J)</li> <li>- Problem Definition Question and rating scale (Appendix K)</li> <li>- Guidelines for raters to rate parents' definitions of problems (Appendix AC)</li> <li>- Data capture and rating sheet for problem definition question (Appendix L)</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>- In addition to both recordings, Rater 1 was given Appendix AB to evaluate procedural consistency in the implementation of the three measures in the pre-and-post-training interviews, and data capture.</li> <li>Measurement consistency               <ul style="list-style-type: none"> <li>- Rater 2 scored the first participant's video-recording and second participant's audio-recording with the transcript, whilst Rater 3 did the opposite.</li> <li>- The raters were required to motivate for scores selected in every category by recording key information in the spaces provided in the data capture and rating sheet. Thus, in the event of marked differences between scores for a category, raters' motivations would be used as the basis for discussion and negotiation.</li> <li>- Raters were familiarized with the rating process for both measures during rater training (discussed in Section 3.4.2.3.3. Appendix AC provided a step by step outline of the process that raters needed to follow to rate parents' problem definitions.</li> <li>- At the end, raters were required to evaluate the following points, after rating parents' orientation (questions B1 &amp; B4) and problem</li> </ul> </li> </ul>	<p>(i.e. 45 minutes per interview), whilst the researcher took <i>50 minutes</i> (25 minutes per interview). However, the time taken by both raters for rating the post-training interviews was 30-35 minutes per participant. Thus a significant decrease was noted as both external raters' rating skills increased.</p> <ul style="list-style-type: none"> <li>- The external raters experienced minor difficulties in following the steps required during the pre-training rating process for the problem definition question (e.g. the recording of participant's verbal statements on the data capture and rating sheet). Once it was explained, no further problems were noted. The latter highlighted the importance of the researcher being available to manage queries during the rating process.</li> <li>- Inter-rater consistency in coding responses was achieved at 82% for the Problem Definition Question, and 100% for the Problem Orientation Questionnaire.</li> <li>- Initially, raters found the transcript most useful, as they referred to it very frequently during the rating process. However, as they became more confident in using the rating system, they indicated that the audio-recording only would be easier and most efficient. There were no major differences in the scores using video-recordings and audio-recordings. Raters found video-recordings to be more-time consuming.</li> </ul>	<ul style="list-style-type: none"> <li>- <b>Inter-rater consistency ratings were reliable for the main study</b></li> <li>- <b>For the main study, only audio-recordings of pre- and post-training interviews will be used. The researcher needs to be available to raters, to answer any queries that may arise during the rating process.</b></li> </ul>

Objectives	Materials and Equipment	Procedures	Results	Recommendations
		definition skills in the pre-and-post training interviews: <ul style="list-style-type: none"> <li>• time taken to complete one participant</li> <li>• ease with which the scoring criteria and guidelines were understood, for both measures</li> <li>• Which of the following would make the rating process easier: (a) video-recording; (b) audio-recording and transcript; (c) audio-recording only; (d) transcript only.</li> </ul>		
To evaluate the ease of coding data pre- and post-training from closed-ended questions in the Biographical Information Questionnaire and Problem Orientation Questionnaire.	- Biographical Information Questionnaire - Problem Orientation Questionnaire	The researcher coded all data from both measures. These codes were checked by Rater 1 for all data.	No problems were encountered with coding closed-ended questions.	<b>No modifications were required.</b>
To test the proposed methods for data capture, data analysis and interpretation	- Biographical Information Questionnaire - Problem Orientation Questionnaire - Problem Definition Question	The data from the three measures were captured onto Excel spreadsheet for data analysis. Data capture was checked by Rater 1. The methods proposed for data analysis could not be followed as planned due to the small sample size (i.e. two participants). Mean scores were thus calculated and analyzed qualitatively to explore the effect of training on the two dependent	No problems were encountered with data capturing and recording onto excel spreadsheets for the two dependent variables.	<b>No modifications were required for data capturing.</b>

Objectives	Materials and Equipment	Procedures	Results	Recommendations
		variables (i.e. problem orientation and problem definition).		
<i>With respect to the pilot training sessions, the following objectives were set:</i>				
To determine the content validity of the Problem Orientation Questionnaire, Problem Definition Question and the training plan	<ul style="list-style-type: none"> <li>- Problem Orientation Questionnaire</li> <li>- Problem Definition Question</li> <li>- Guidelines for raters to rate parents' problem definitions (Appendix AC)</li> <li>- Training plan (Appendix U)</li> </ul>	In order to ensure that the training plan targeted the desired outcomes of the two measures, the researcher compared the questions on the Problem Orientation Questionnaire, and the guidelines for rating parents' problem definitions, to the different components in the training plan. The components in the training plan were to be used in the main study as well.	All questions and ratings were targeted both primarily and secondarily in different components of the training plan (refer to Appendix U). Thus, the content validity of the interview schedules and training plan were established.	<b>No modifications required for the main study.</b>
To determine the suitability of the training context in terms of extraneous noises and distractions; technical facilities, capacity to accommodate all participants during training.	Training room	The researcher made observations relating to booking the venue, distractions; seating and technical facilities necessary for using the training aids.	Training took place at a public hospital – a venue similar to that planned for the main study. However, to fit in with participants' care-giving responsibilities, training was offered over three days, and training times varied from three to four hours per day. Thus, the four-day training program planned for the main study could not be implemented. The researcher transported the participants to the venue. The room was equipped with the required technical facilities, accommodated the seating of two participants, trainer and training assistant with ease, and there were minimal distractions.	<b>Training within a public hospital context did not present with any major problems.</b>
To test the clarity of instructions given to participants regarding	<ul style="list-style-type: none"> <li>Power-point slide</li> <li>Handout</li> <li>Pilot training evaluation form</li> </ul>	The researcher read the instructions from the slide. Participants were asked to rate the clarity of instructions on a 4-point scale:	Participants indicated that instructions were always clear (rating = 4).	<b>No modifications were recommended.</b>

Objectives	Materials and Equipment	Procedures	Results	Recommendations
small group discussions during training		1 = not clear at all 2 = clear some of the time 3 = clear most of the time 4 = always clear		
To determine the clarity of instructions given to participants prior to viewing the videos.	Power-point slide	The researcher read the instructions from the slide. In addition participants were given a question to guide their observations of key teaching variables when watching the videos (for example, positive outlook despite difficult conditions; not blaming self, feeling in control. Feeling good about self, etc.) Participants were asked to rate the clarity of instructions on a 4-point scale: 1 = not clear at all 2 = clear some of the time 3 = clear most of the time 4 = always clear	Participants indicated that instructions were clear all of the time (rating = 4).	<b>No modifications were recommended</b>
To determine the suitability of teaching methods used during training: - small group discussions - parents' stories - constructive feedback - guided reflection - cognitive restructuring - lectures using power-point slides - case study (warrior mum) - evaluation of video materials	Power-point slide Handout	Refer to Appendix Q for detailed description of the training methods. <i>Lectures</i> and open discussions were used to introduce the topic of help-seeking and problem solving, and the critical significance of the first two components: problem orientation and problem definition. Each were defined and discussed – using an example derived from different participants' responses on the pretest (problem orientation questionnaire and problem definition question).	Participants rated teaching methods as very suitable (score of 4), and indicated that they enjoyed participating. They were able to identify their own learning goals for the next session, and collaborated with the trainer in identifying assignments tasks that could be done at home during the week.	<b>No modification required.</b>

Objectives	Materials and Equipment	Procedures	Results	Recommendations
<p>- setting goals linked to homework assignments            - handout (Getting the help you need when talking to professionals)</p>		<p><i>Parents' stories</i> were used to allow parents to build rapport and identify with each other, recognize similarities and differences in experiences, and identify coping strategies, etc.</p> <p>Case study of a warrior mum was used to illustrate similarity of problems confronted by people in other contexts, not only parents of children with disabilities. It was used to highlight the versatility of training in help-seeking and the crucial significance of maintaining a positive outlook irrespective of the situation.</p> <p>During <i>small group discussions</i> participants were asked to discuss specific questions relating to: experiences in parenting their child; attitudes towards their child's disability; coping strategies used; stating problems and required solutions to health professionals (e.g. SLT). The strategies of constructive feedback, guided reflection and cognitive restructuring were used to facilitate positive orientations and definitions.</p> <p>During <i>observations of videos</i>, participants were asked to list three things that they found important and could use to improve their orientations.</p>		

Objectives	Materials and Equipment	Procedures	Results	Recommendations
To examine whether participants found the video material and power-point slideshows useful and easy to understand	<p><i>Videos:</i></p> <ul style="list-style-type: none"> <li>- You-tube video: “Are you going to finish strong”</li> <li>- Video 1: confident parent sharing positive experiences of ECCI</li> <li>- Video 2: Simulation of a parent with positive orientation and good problem definition skills</li> <li>- Video 3: Simulation of a parent with negative problem orientation and poor problem definition skills</li> </ul> <p><i>Power-point slideshow:</i></p>	<p><i>Identifying learning goals and homework tasks</i> were done via individual discussions at the end of the session. Report back occurred at the beginning of training sessions. Participants were asked to use a 4-point scale to rate the suitability of the training methods used to achieve the aims of training:</p> <ul style="list-style-type: none"> <li>1= not suitable at all</li> <li>2 = somewhat suitable</li> <li>3 = largely suitable</li> <li>4 = very suitable</li> </ul> <p>Refer to Appendix Q for a detailed description of the videos and power-point slideshow. Participants were asked to rate the material as:</p> <ul style="list-style-type: none"> <li>1= not useful, difficult to understand</li> <li>2 = somewhat useful, some parts were understandable</li> <li>3 = very useful, easy to understand</li> </ul>	<p>- Participants gave the materials a rating of 3 (very useful and easy to understand). They indicated that they enjoyed the videos and power-point slideshows. They recommended including more slideshows as it made the concept of problem orientation meaningful. Visual materials were enjoyable and fun, and facilitated shifts in parents’ awareness and thinking.</p>	<p><b>No modification required to current video materials, but recommend adding further power-point slideshows for the main study.</b></p>

Objectives	Materials and Equipment	Procedures	Results	Recommendations
To test the use of the following during training: power-point slides (font size, colours, etc.); laptop, position of the screen and projector, and dvd/video materials.	<p>- “We are like pencils”</p> <p>- Laptop: HP, Compaq 6720s</p> <p>- Projector: Optoma, EW610ST</p>	The researcher observed factors that facilitated or hindered the use of each.	No problems were encountered with any of the items listed.	<b>No modifications required.</b>
To evaluate the sequencing and pacing of the training content, and the overall length of time taken to complete each training session.	<p>Video material</p> <p>Training program me outlined in Table 13 and Appendix U.</p>	The researcher monitored the sequencing, pacing and length of each training session. The entire training programme was evaluated over three days, rather than the four days planned for the main study.	No problems were encountered with the sequencing of the training content. However, pacing was somewhat problematic as general discussions were shortened to ensure that the planned content was completed. Training occurred over 4 hours on Day 1, and three hours on Days 2-3. There was a four day gap between Day 1 and Day 2, and the trainer had to spend time on Day 2 to review the content covered on Day 1. Parents were generally happy with the pacing of the program me, but felt that four hours per day would be better.	<b>The main phase of the study is planned for four training sessions – four hours in duration (09H00 – 13H00). This will ensure that adequate time is given for participants to engage in discussions, and it will be of sufficient duration to ensure that parents are not tired. Recommend that there are no breaks in-between the four training days.</b>
To determine participants’ interest level and perceived benefit from the training sessions	<p>Pilot training evaluation forms:</p> <p>- Training session evaluation form (Appendix V)</p> <p>- General evaluation questionnaire (Appendix W)</p>	<p>- At the end of each training day, participants were required to complete the training session evaluation form to ascertain if they required any changes to be made for the next training day (Appendix V). The evaluation provided feedback on the trainer (loudness, intelligibility; ease in understanding</p>	<p>- Participant evaluation at the end of each day was positive, and no major changes were required.</p> <p>- The two participants rated the overall pilot training programme very positively. Detailed feedback was given for different aspects of the training sessions (preparation of the trainer, length of training, videos, benefits of training,</p>	<p><b>- Besides the allocation of more time for discussions, and increasing training to four hours on each day, no further changes were recommended. Participants generally enjoyed the sessions. For the main study:</b></p>

Objectives	Materials and Equipment	Procedures	Results	Recommendations
		content; training methods used; clarity of videos; pace of training, etc. At the end of the 3 <sup>rd</sup> day of training, participants evaluated the entire training programme (Appendix W)	recommending training to others). One participant requested for more time to practice problem definition during the session. They made particular mention of the value of the videos. Comments in the open-ended question included: <i>"I now know what I can do to help my child"</i> <i>"We need to get this type of training at the hospitals"</i>	<b>- More time was allocated for parents to practice problem definition.</b> <b>- Developed a simple, easy to follow checklist to assist parents in their learning. Outlined the steps and key areas to include in the problem definition process. The checklist was included in the handout.</b>
To determine the ease with which Rater 1 could assess procedural reliability of the training programme	-Video-recordings of the three training days - Integrity of the training programme rating sheet (Appendix Y) - Detailed training plan (Appendix U)	Rater 1 was familiarized with training plan and the rating procedure, as discussed in Table 13, Appendix U and Section 3.4.2.3.3. The rater assessed procedural reliability of the training at the end of each day. Video-recordings were available, if the rater needed to verify any aspect of the assessment.	No problems were noted. Ratings indicated 100% compliance with the training planned for the pilot study. The rater did not need to access the video-recordings.	<b>No modifications for the main study.</b>
<b>To determine whether the pilot training programme influenced parents' orientations to and definitions of problems experienced in parenting young children with moderate to severe communication disabilities</b>	<b>Pre-and-post training administration of:</b> <b>- Problem Orientation Questionnaire</b> <b>- Problem Definition Question</b>	<b>Comparison and careful examination of parents' responses to the pre-and-post-training interview schedules.</b>	<b>The following trends were noted in the two dependent variables after the pilot training:</b> <b>DV1: Problem orientation</b> <b>Pre-training mean scores for the dimensions of problem attribution, personal control and problem appraisal ranged largely from 1-2; for problem perception 2-3, and for commitment of time and effort 4. Post-training mean scores increased to 3-4 for the first four dimensions, whilst the fifth dimension remained unchanged.</b> <b>DV2: Problem definition</b>	<b>The dimensions of problem attribution, personal control and problem appraisal for problem orientation; and all dimensions for problem definition are likely to require greater attention during training in the main study.</b>

Objectives	Materials and Equipment	Procedures	Results	Recommendations
			<p>Pre-training mean score for the dimensions of organization and relevance of information, and overall problem definition was 1. Post-training mean scores for the three areas increased to 3-4.</p> <p>Overall findings indicated that the training had a positive effect on both dependent variables, but the effects were greater for problem definition. For problem orientation, training had a greater effect on the dimensions of problem attribution, personal control and problem appraisal. Thus, core areas of training for the main study include the dimensions of problem attribution, personal control and problem appraisal for problem orientation; and all dimensions for problem definition.</p>	

## Appendix AB

### Rating form for procedural consistency in the interviews and data capture

Please rate the interview process according to the statements below. Place an X in the appropriate column. Thank you.

<b>Interview process</b>	<b>Yes</b>	<b>No</b>
The researcher greeted the parent & introduced herself.		
The researcher briefly explained the purpose of the study and interview again. ( <i>The resident therapist had already explained in detail and obtained parents' verbal consent</i> ).		
The informed consent form was filled in and signed by the parent, researcher and resident therapist as witness.		
The researcher explained reasons for video-recording and/or audio-recording the interview.		
The researcher briefly explained the three parts of the interview (biographical information, problem definition and orientation to problem)		
Instructions for the <b>Biographical Information Questionnaire</b> were provided according to the interview schedule.		
All questions in the Biographical Information Questionnaire were read and recorded according to the sequential order in the questionnaire.		
The parent was given sufficient time to answer all questions		
Instructions for the <b>Problem Definition</b> Question were provided according to the interview schedule.		
Probing was only done to obtain clarity of information already given, and not to introduce new areas of information.		
The parent was given sufficient time to answer questions.		
Instructions for the <b>Problem Orientation Questionnaire</b> were provided according to the interview schedule.		
All questions in the Problem Orientation Questionnaire were read and completed according to the sequential order in the questionnaire.		
The parent was provided with an enlarged copy of the Problem Orientation Questionnaire to facilitate the scanning of response alternatives and selection of the most appropriate response for the parent.		
The parent was given sufficient time to answer questions.		
All response options were clearly read out.		
Parents' questions were answered in a non-biased manner.		
The parent was informed about further arrangements with respect to the training programme (where applicable) and post-training interviews.		
At the end of the interview, the parent was thanked and given a financial incentive (R20) to assist with transport costs.		
<b>Data Capture Process</b>		
Parent responses were accurately captured for all questions		

## Appendix AC

### Guidelines for raters to rate parent's definitions of problems

1. Familiarize yourself with the **scoring criteria** proposed in Appendix K, for rating parent's definitions of problems. There are **two main sections** that need to be scored:
  - 1.1 **Organization of information** (section one in the data capture and rating sheet – see Appendix L): refers to parents' skill in describing the problem in an organized manner (i.e. sequenced logically, developmentally, and cohesively), to promote the SLT's understanding of the problem.
  - 1.2 **Relevance of information** (section two in the rating sheet): refers to how specific, concrete and comprehensive parents' descriptions are, to help the SLT in planning effective and sustainable early communication intervention. At this level, parents may provide information on the child's *communication disability*, as well as *other associated problems* (e.g. financial constraints, family support, etc.). Record the information in the relevant areas.
2. Listen to the **audio-recording** of parents describing their problem and the help that they need.
3. Commence by **rating the relevance of the information first** (i.e. section two). Record information in each of the three main categories: **specificity** of information; use of **concrete information** and **comprehensiveness** of information. Tick each section to indicate that the parent included it in the description. Thereafter record key information from the parent's description in the spaces provided. The latter will assist you in scoring the section. Record your score for each category only, do not add scores.
4. Rate section one, namely, **how well the parent organizes the information** when describing the problem. To help you with the rating, briefly write down what parents say with respect to each of the following areas: (1) what is the problem, for whom and why; (2) what changes are desired, by whom and why; and (3) what obstacles make it difficult for the child and parent to acquire the desired level of communication. Record your score.
5. Follow the above procedure for rating each participant. Once all interviews are completed, contact me and I will collect the data capturing and rating sheets. You may also email the sheets to me if you complete it electronically. Email sheets to [moodleyl@ukzn.ac.za](mailto:moodleyl@ukzn.ac.za)
6. If you have any further queries, please contact me at: (H): 031-2091882 (W) 031-2607387  
Thank you for your assistance with capturing and rating parents' definitions of problems and needs.

**100**  
1908 - 2008



UNIVERSITEIT VAN PRETORIA  
UNIVERSITY OF PRETORIA  
YUNIBESITHI YA PRETORIA

Faculty of Humanities  
Research Proposal and Ethics Committee

2 March 2009

Dear Prof Uys,

**Project:** Facilitating problem definition: impact on families' perceptions of needs, resources and problems experience in caring for young children with disabilities  
**Researcher:** L Moodley  
**Supervisor:** Prof. CJE Uys  
**Department:** Centre for Alternative and Augmentative Communication  
**Reference number:** 95271954

Thank you for your correspondence of 16 February 2009.

I have pleasure in informing you that the Research Proposal and Ethics Committee formally **approved** the above study at an *ad hoc* meeting on 27 February 2009. The approval is subject to the candidate abiding by the principles and parameters set out in her application and research proposal in the actual execution of the research.

The Committee requests you to convey this approval to Ms Moodley.

We wish you success with the project.

Sincerely

**Prof. Brenda Louw**  
**Chair: Research Proposal and Ethics Committee**  
**Faculty of Humanities**  
**UNIVERSITY OF PRETORIA**  
**e-mail: [brenda.louw@up.ac.za](mailto:brenda.louw@up.ac.za)**

**Title change registration**

Our ref: Ms P Woest / 95271954  
Tel: 012 420 2736  
Fax: 012 420 2698  
E-mail: petru.woest@up.ac.za



UNIVERSITEIT VAN PRETORIA  
UNIVERSITY OF PRETORIA  
YUNIBESITHI YA PRETORIA  
**Faculty of Humanities**

4 May 2011

Ms L Moodley  
63 Ward Road  
OVERPORT  
DURBAN  
4091

Dear Ms Moodley

**TITLE REGISTRATION: FIELD OF STUDY – DPHIL IN COMMUNICATION PATHOLOGY**

I have pleasure in informing you that the following has been approved:

**TITLE OF THESIS:** A training programme to facilitate parents' orientation to and definition of problems experienced in parenting young children with moderate to severe communication disabilities

**SUPERVISOR:** Prof CJE Uys

**CO-SUPERVISOR:** Prof E Alant

**PLEASE TAKE NOTE OF THE FOLLOWING INFORMATION AS WELL AS THE ATTACHED REQUIREMENTS.**

1. **PERIOD:**
  - (a) You must be enrolled as a student for at least one academic year before submission of your thesis.
  - (b) Your enrolment as a student must be renewed annually before 31 March, until you have complied with all the requirements for the degree. You will only be liable to have supervision if you provide a proof of registration to your supervisor.
2. **NOTIFICATION BEFORE SUBMISSION:**

You are required to notify me at least three months in advance of your intention to submit your thesis.
3. **APPROVAL FOR SUBMISSION:**

On completion of your thesis enough copies for each examiner as well as the prescribed examination enrolment form which includes a statement by your director of studies that he/she approves of the submission of your thesis, as well as a statement, signed by you in the presence of a Commissioner of Oaths, must be submitted to Student Administration.
4. **DATE OF EXAMINATION:**

If your doctoral examination is to take place after the submission of your thesis, please inform me of the date of the examination.

Yours sincerely

for DEAN: FACULTY OF HUMANITIES

GW-606E



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YUNIBESITHI YA PRETORIA

Permission from South African Department of Health

# DEPARTMENT OF HEALTH

PROVINCE OF KWAZULU-NATAL

SPECIAL SUPPORT SERVICES

Natalia, 330 Longmarket Street, Pietermaritzburg, 3201  
Private Bag X9051, Pietermaritzburg, 3200  
Tel.: 033 395 2813, Fax.: 033 345 4433

Enquiries: Miss A. Kopman  
Extension: 2813  
Reference: 9/2/3/R

09 DEC 2005

Ms Legini Moodley  
University of KwaZulu-Natal  
Discipline of Speech-Language Pathology  
School of Audiology, Occupational Therapy  
Private Bag 7  
**CONGELLA**  
4013

Dear Madam

## PERMISSION TO IMPLEMENT STUDY WITH OUTPATIENTS RECEIVING SPEECH-LANGUAGE THERAPY SERVICES AT PROVINCIAL HOSPITALS AND ASSESSMENT CENTERS

Your facsimile dated 06 December 2005 refers.

Please be advised that authority is granted for you to conduct a research study "Permission to implement study with outpatients receiving speech-language therapy services at provincial hospitals and assessment centers" provided that :-

- (a) Prior approval is obtained from the Heads of the institutions and assessments centers;
- (b) Confidentiality is maintained;
- (c) The Department is acknowledged; and
- (d) The Department receives a copy of the report on completion.

Yours sincerely

  
SUPERINTENDENT-GENERAL  
HEAD : DEPARTMENT OF HEALTH  
AJK/moodley

Umnango Wezempilo

Departement van Gesondheid



## **Appendix AF**

### **Informed consent form for the main study**

#### **A training programme to facilitate parents' orientation to and definition of problems experienced in parenting young children with moderate to severe communication disabilities**

##### **Information for Participant**

Thank you for volunteering to participate in the above study.

As a parent of a young child with a moderate to severe communication disability, you are aware of the many problems that you face on a daily basis in caring for her/him. You may have talked to many people (health professionals and others) to help you cope with these problems. Parents must be skilled in getting the help that they need for their child. This is important to ensure that your child reaches his/her full developmental potential. This study focuses on your ability to talk to professionals about your problems, so that they are able to give you the help that you need to care for your child. By participating in this study, you will learn how to talk about your problems in a clear, confident manner. You will also give speech-language therapists important information that can be used to train other parents in getting the help that they need for their children with moderate to severe communication disabilities.

##### **Informed Consent Form**

**1. Title of study:**

A training programme to facilitate parents' orientation to and definition of problems experienced in parenting young children with moderate to severe communication disabilities

**2. Purpose of study**

To determine the impact of training in facilitating parents' orientation to and definition of problems experienced in parenting young children with moderate to severe communication disabilities

**3. Procedure:**

A quasi-experimental, non-equivalent groups pre-test-post-test control group design will be used. The study will be conducted in 3 parts:

**Part 1:** Interviews will be conducted to determine how you approach and talk about the problems that you experience in parenting your child with moderate to severe communication disabilities

**Part 2:** You will attend a training programme on problem orientation and definition, together with other parents who also have a young child with a communication disability. The programme will involve sharing of information and ideas between parents and the trainer so that you learn to use positive ways of approaching and talking about problems. In this way you get the help that you need from speech and language therapy programmes.

**Part 3:** A second interview will be conducted one week after the training, and will be similar to the first interview.

*Please note:* Two groups of parents will participate in this study. You will be informed about which group you are in. If you are in Group 1 (experimental group), you will receive the training programme approximately two weeks after the first interview. If you are in Group 2 (control group), you will receive the training programme after the second interview – at a time that is suitable to parents.

**4. Risks and discomforts:**

There are no known medical or psychological risks in this study. However, if for any reason the interviews or training programme make you to feel that you require counseling, this service will be provided by a trained counselor immediately after the study is completed.

**5. Benefits**

By participating in this study, you will learn how to approach and talk about your problems to speech-language therapists and other health professionals, so that you get the help that you need. You will learn how to cope positively in parenting children with moderate to severe communication disabilities. You will also be helping speech-language therapists so that they can develop and provide similar training opportunities to other parents who have children with communication disabilities.

**6. Participant's rights:**

You have the right to withdraw from participating in this study at any time.

**7. Confidentiality and Anonymity**

All information collected during the study from the interviews and your hospital/clinic records will remain strictly confidential. Your identity will not be revealed as your name will not be used in the report. Instead, you will be identified by a number, for example, participant 1. The interview sessions and parts of the training programme will be video and audio-recorded. The researcher and research supervisors at the University of Pretoria will have access to these recordings. If you request, the recordings will be made accessible to you. Upon completion of the study, the recordings will be stored in a research data-base at the University of KwaZulu-Natal, and may be used for further research programmes at a later date. Your permission will be requested before such use. However, should you not agree to the latter, the recordings will be destroyed.

**8. Additional Queries**

If you have any further queries or concerns, the researcher can be contacted as follows:

**Work:** (031) 2607623    **Fax Number:** (031) 2607622    **Email:** [moodleyl@ukzn.ac.za](mailto:moodleyl@ukzn.ac.za)

I understand my rights as a participant in this study, and I am willing to participate in the research process as stipulated in this document. I understand the nature of the study, the motivation for the study and the manner in which it will be implemented. I will receive a signed copy of this consent form.

\_\_\_\_\_  
Participant's signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Researcher's signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Witness

\_\_\_\_\_  
Date

## Appendix AG

### Trainer's reflective diary

The following excerpt illustrates the nature of the entries.

#### Reflections on the training programme:

##### Training Day 1:

- Setting up the venue: Arrived at the venue early, able to do this well within time. Were ready/set-up by the time the parents started arriving. Decided to commence 30 minutes later (9.30 instead of 9.00) as there was a traffic jam which affected transport to the venue...many parents were arriving late. Used the time to introduce parents to each other. By 9.30am, all parents arrived.
- Help from venue staff was excellent, cleaned venue and toilets
- One parent notified me yesterday of transport difficulties. Made arrangements to fetch her.
- Technology: everything worked well.
- Assistants worked well. Catering well organized.
- Program: Parents did not know each other. Very reserved and quiet.
- I shared my interest in ECI and parents told their stories. Very disturbing. Many cried. Although we were running over time, they continued. Wanted to tell their stories. All were comfortable to come to the front and tell their story, nobody refused. One parent started and set the tone.
- I felt very disturbed after listening to their stories.
- Key issues that arose from stories: lack of family support, limited financial resources, people don't understand disability – blame parents (cultural explanations e.g. one child was cut many times to appease the ancestors, etc.); mothers treated very badly by families for having a child with a disability “like rubbish”; some are just overwhelmed, don't know what to do/how to cope; professionals don't really understand their issues, don't take the time to understand their problems, therefore don't have trust in them, asked to do things that they cannot do; strategies given don't help. For example, for feeding, some mothers developed their own strategies (e.g. stimulating the gums, lips etc, positioning cerebral palsy child; major problem of behaviour/tantrums in autistic children - parents don't know how to cope:
- Tomorrow has to be about solutions....taking them forward.
- Training session evaluation forms – very positive.
- Lucky draws – lightened the mood.

##### Training Day 2:

- the way forward in developing a positive attitude.
- Day was very positive. Parents said they felt lighter. They were in a very good mood. Starting to make friends, talking to each other. A lot of sharing of tips that worked for them. For example, how to manage a child who has epileptic attacks (e.g. identifying the early warning signs of an imminent attack and averting a major attack); stimulating oral structures for feeding; positioning CP child for feeding.

- Parents raised other issues that made parenting difficult, e.g. husbands not supportive, poor family support – wanted to know how to deal with these issues; want to meet other mothers
- Tea-time – facilitated parents talking to each other.
- Went through positive ways of approaching problems (positive orientations) – identified significance for building resilience.
- Gave parents gratitude journals.
- Had presentation by cancer survivor, how she coped with diagnosis of breast cancer. Made parents see that there are others battling bigger problems (mortality). She emphasized what she did to cope positively on a day to day basis, what she did on the bad days. Music and reading inspirational books were critical for her. She had a favourite song, which she called “My theme song”...made her feel strong to go on, when she felt depressed.
- Many parents said that they also used music to help them de-stress. Parents liked the idea of having a theme song for themselves...indicated that they would do so for themselves as well.

## Appendix AH

### Detailed description of the reliability of data collected

As outlined in Chapter 3 Section 3.4.2.5, the following five levels of reliability testing were followed at stage two of data analysis, to establish the integrity of the data for analysis and meaningful interpretation (Schlosser, 2003; McMillan & Schumacher, 2010; Leedy & Ormrod, 2013).

#### ***Level 1: Parents' response rate***

There was a *100% response rate for the pre-and-post training interviews* in the experimental and control groups (n=34), which was consistent with using interviews as the method of data collection (McMillan & Schumacher, 2010). In addition, 100% of parents in the experimental group attended the four days of training (n=15). The response rates for both the interviews and training provide a solid basis for engagement in meaningful interpretations and conclusions.

#### ***Level 2: Procedural consistency of the pre-and-post-training interviews, data capture and training programme***

Procedural consistency in the implementation of the pre-and-post training interviews, data capture and training programme was evaluated by Rater 1 (i.e. the trained research assistant).

**Procedural consistency in the implementation of the pre-and-post-training interviews and data capture:** Rater 1 listened to the audio-recorded interviews on the day that interviews were completed during pre-and-post training. The rater used a four-point Likert scale (1=poor; 2=satisfactory; 3=good; 4=very good), and rated whether interviews were implemented as planned in Sections 3.4.2.4.1 and 3.4.2.4.3, and participants' responses were captured accurately for closed ended questions in the Biographical Information Questionnaire and Problem Orientation Questionnaire. Rater 1 also transcribed the two open-ended questions B1 and B4 in the Problem Orientation Questionnaire, into the space provided in the questionnaire. The consistency of the transcriptions with the audio-recordings was evaluated by the researcher. The specific areas assessed and the results are presented in Appendix AI. Findings reflect that procedural consistency

of the pre-and-post-training interviews and data capture were very good (rating of 4). The findings were expected as the questionnaires were implemented using a structured interview format (McMillan & Schumacher, 2010).

**Procedural consistency in the implementation of the training programme:** The integrity of the training programme was evaluated in terms of the trainer and participants (Sanetti et al., 2009; Forgatch et al., 2005). The evaluation determined consistency in two aspects during the four training days: (i) the trainer's competence (i.e. knowledge, teaching and clinical skills), and implementation of the training plan as set out in Appendix U; and (ii) the participants' attendance, interest and active engagement in the training process and completion of home assignments.

Rater 1 (research assistant) was present on the four days and rated training on a four-point Likert scale (1=poor; 2=satisfactory; 3=good; 4=very good). This was done using the integrity of the training programme rating form, at the end of every day. The results of the ratings for the four days are presented in Appendix AJ. The findings reflect a mean rating of 3.98, showing that the training plan was followed very closely for the four training days, and that parent participation was very high. Thus, the probability of training influencing parents' orientation to and definition of problems is positive, after consideration of any confounding variables.

### **Level 3: Measurement consistency in the rating of open-ended questions in the Problem Orientation Questionnaire and Problem Definition Question**

External raters 2 and 3 received the audio-recordings of the pre-and-post training interviews in two sets, but were blind to the status (i.e. pre-or-post training). Both raters evaluated open-ended questions B1 and B4 in the Problem Orientation Questionnaire, and parents' responses to the open-ended Problem Definition Question. The integrity of the ratings was established using reliability measures of **inter-rater and intra-rater percentage agreement** (McMillan & Schumacher, 2010; Schlosser, 2003). Inter-rater percentage agreement established measurement consistency between the two rater's ratings, whilst intra-rater percentage agreement established if the ratings for audio-recordings that were done initially were consistent with those of audio-recordings that were done towards the end of the rating process,

for each rater . The formula by Schlosser (2003) was used to calculate inter-rater percentage agreement:

$$\text{Inter-rater percentage agreement} = \frac{\text{number of agreements}}{\text{number of agreements} + \text{number of disagreements}} \times 100\%$$

Although the ratings of 20-40% of data was considered adequate (Schlosser, 2003), ratings for both measures were done for all interviews [(n=34)x2=68 interviews). Intra-rater coding-recoding percentage agreement was calculated using Schlosser’s formula as well. Results are presented for each measure.

### ***Problem Orientation Questionnaire (Questions B1 & B4 in Appendix J)***

Inter-rater agreement was 100% for coding both questions in both interviews, implying that data reflecting parents’ perceptions of initial and maintaining causes of their children’s communication disability were reliable.

### ***Problem Definition Question***

Inter-rater agreement in coding was assessed for the two dimensions and the respective sub-dimensions of the problem definition variable, as described in Table AH1.

Table AH1

#### *Computation of inter-rater agreement reliability for problem definition*

<b>Problem Definition Variable - dimensions and sub-dimensions</b>	<b>Areas assessed for inter-rater and intra-rater agreement reliability (refer to Appendix L)</b>
<b>Dimension 1: Organization of information</b> <i>(Important in facilitating the SLT’s understanding of the problem)</i> <b>Three sub-dimensions:</b> (a) what is the problem, to whom and why; (b) what is the desired outcome, to whom and why; and (c) what obstacles prevented attainment of desired outcomes for the child and parent	<b>Overall organization of information in the three sub-dimensions</b> A 4-point-Likert scale was used with scores ranging from well organized and thus easily understood by the SLT (4), to poorly organized and thus difficult for the SLP to understand (1).
<b>Dimension 2: Relevance of information</b> <i>(Important for planning effective and sustainable communication intervention)</i> <b>Three sub-dimensions:</b> (a) specificity of information, (b) operationalization/ concreteness of information, and (c) comprehensiveness of information.	<b>Inter-rater agreement reliability in the following three areas were established:</b> <b>(a) Relevance of information in each sub-dimension of dimension 1.</b> <i>(three scores for relevance of information in each sub-dimension of dimension 1 were averaged – see 2.1; 2.2; 2.3 in Appendix L)</i> <b>(b) Overall level of specificity, operationalization and comprehensiveness of information across the</b>

<b>Problem Definition Variable - dimensions and sub-dimensions</b>	<b>Areas assessed for inter-rater and intra-rater agreement reliability (refer to Appendix L)</b>
	<p><b>three sub-dimensions of dimension 1</b> (V54, V55 V56 in Appendix L)</p> <p>A 4-point Likert scale was used to rate each sub-dimension, with scores ranging 4 to 1 (i.e. high to low levels of specificity, operationalization and comprehensiveness, respectively)</p> <p>(c) <b>Overall relevance of information across the three sub-dimensions of dimension 1</b> (V57 -(average score for ratings of V54, V55, V56)</p>
<b>Overall rating of parent’s problem definition</b>	<p><b>Ratings of dimensions 1 and 2 were averaged.</b> Both dimensions were weighted equally, as both are considered equally important in facilitating the SLT’s understanding of the problem (D’Zurilla &amp; Nezu, 1999).</p>
	<p><b>Intra-rating reliability:</b></p> <p>To control for practice effects in coding, raters recoded the two dimensions of problem definition for five of the initial 10 audio-recordings done</p>

The results for each area identified in Table AH1 is presented:

(i) *Inter-rater agreement in coding Dimension 1 of problem definition (i.e. organization of information)*

External ratings of parents’ organization of information when defining problems *before training*, is reflected in Table AH2 for all participants in the experimental and control groups ( $N = 34$ ).

Table AH2

*Inter-rater agreement in coding parents’ organization of information*

<b>Categories for rating parents’ organization of information (Dimension 1)</b>	<b>Inter-rater agreement in pre-training interviews</b>	
	<b>Rater 2 % (N=34)</b>	<b>Rater 3 % (N=34)</b>
<b>1 poor</b>	32% (11)	32% (11)
<b>2 moderately poor</b>	<b>35% (12)</b>	<b>44% (15)</b>
<b>3 moderately good</b>	32% (11)	24% (8)
<b>4 good</b>	-	-
<b>Inter-rater agreement</b>	<b>91% [31/(31+3)]</b>	

Table AH2 reflects 91% agreement between both raters for the coding of parents’ organization of information in 31 participants in the sample. The raters differed in ratings for 8.82% or 3 participants, with Rater 2 scoring 3 (moderately good) and Rater 3 scoring 2 (moderately poor).

After comparison with the researcher's score as a reliability check, the rating of 3 was taken as the final score. The high inter-rater agreement of 91% at the outset demonstrates very good reliability of the data for dimension 1 of the problem definition construct, during the pre-training interview.

*(ii) Inter-rater agreement in coding Dimension 2 of problem definition (i.e. relevance of information)*

External ratings of the relevance of information contained in parents' definitions of problems were computed at three stages (including an overall score for relevance of information), as described in Table AH1. Results are presented for each stage and reflected in Tables AH3, AH4 and AH5 respectively. Mean and standard deviation values were computed using the raters' raw scores for 34 parents in the pre-training interview. The paired t-test was used to establish whether there was a significant difference between the raters. Results for each stage are presented.

*Stage 1: Inter-rater agreement in coding the relevance of information contained in the three sub-dimensions of Dimension 1 (i.e. organization of information)*

Table AH3 illustrates the inter-rater agreement in coding the relevance of information contained in each of the three sub-dimensions of Dimension 1 *before training* – that is, what is the problem, what outcomes are desired and what obstacles hinder the attainment of desired outcomes.

Table AH3

*Inter-rater agreement in coding the relevance of information in the three sub-dimensions of Dimension 1 (i.e. organization of problem definition)*

Relevance of information in the three sub-dimensions in Dimension 1 of problem definition ( <i>organization of information</i> )	Inter-rater agreement in the pre-training interviews (n=34)	
	Rater 2	Rater 3
<b><i>Sub-dimension 1</i></b>		
<b>What is the problem and why?</b>		
Mean	1.8	1.7
Standard deviation	0.7	0.6
t-test		2.8
p value		<b>*0.01</b>
<b><i>Sub-dimension 2</i></b>		
<b>What is the desired outcome?</b>		
Mean	1.5	1.5
Standard deviation	0.6	0.6
t-test		-0.17
p value		<b>0.9</b>
<b><i>Sub-dimension 3</i></b>		
<b>What obstacles hinder desired outcomes?</b>		
Mean	1.4	1.3
Standard deviation	0.6	0.6
t-test		2.24
p value		<b>*0.03</b>

\* statistical significance at the 5% confidence level

Findings indicate complete agreement between raters for sub-dimension 2, namely, parents' descriptions of desired outcomes. The finding implies that parents' were more skilled in providing specific, concrete and comprehensive information about what they wanted from intervention. When combined, the three sub-dimensions contributed to information being relevant. The raters were able to identify the sub-dimensions easily, thus facilitating inter-rater agreement. Differences were seen in the ratings of sub-dimensions 1 and 3 for Dimension 1, with Rater 2 scoring parents' descriptions of the problem (i.e. sub-dimension 1) and obstacles that hindered desired outcomes (i.e. sub-dimension 3), as slightly more relevant compared to Rater 3. Although marginal, the differences were significant ( $p=0.01$  and  $p=0.03$  at the 5% level respectively). These findings imply that parents may not have provided information that was specific, concrete and comprehensive about their problems and the obstacles that hindered problem resolution, in the manner required to facilitate intervention planning. The raters therefore had less information to aid

decision-making about the relevance of parents' information for intervention planning. Thus, the raters may have relied on other clinical resources to support decision-making, thereby contributing to differences in inter-rater agreement. The raters' clinical experience and expertise is discussed further in Section 5.2.2, as a clinical resource in supporting decision-making.

*Stage 2: Inter-rater agreement in coding the sub-dimensions of Dimension 2 (i.e. specificity, concreteness and comprehensiveness of information)*

Table AH4 outlines the external ratings for the three sub-dimensions, namely, specificity, concreteness and comprehensiveness of information in parents' problem definitions *before training*.

Table AH4

*Inter-rater agreement in coding the sub-dimensions of Dimension 2 (specificity, concreteness and comprehensiveness of information)*

Sub-dimensions of Dimension 2: <i>Relevance of information</i>	Inter-rater agreement in the pre-training interviews (n=34)	
	Rater 2	Rater 3
<b>Specificity of information</b>		
Mean	1.6	1.6
Standard Deviation	0.6	0.6
t-test		0.99
p value		<b>0.3</b>
<b>Operationalization/ concreteness of information</b>		
Mean	1.6	1.5
Standard Deviation	0.6	0.5
t-test		2.11
p value		<b>*0.04</b>
<b>Comprehensiveness of information</b>		
Mean	1.5	1.5
Standard deviation	0.5	0.5
t-test		0.08
p value		<b>0.9</b>

Note: \* statistical significance at the 5% confidence level

Results reveal *no significant differences in the raters' coding* for two of the three sub-dimensions, namely, *specificity* and *comprehensiveness* of parents' definitions. The finding implies that raters could easily identify information that was *specific and comprehensive* in parents' definitions of problems. For the sub-dimension of operationalization / concreteness of

information, although the difference in mean values was marginal, it was significant ( $p=0.04$ ) - implying that the identification of operational or concrete information in parents' problem descriptions appeared to be slightly more challenging for the raters. Operational or concrete information refers to parents' descriptions of examples of the child's communication behaviours or other associated problems, as it actually occurs in specific contexts. The examples enable the SLT to develop an in-depth understanding of the problem. Similar to Stage 1, the difference in the raters' clinical experience may account for differences in inter-rater agreement and is discussed further in Section 5.2.2.

*Stage 3: Reliability of coding for Dimension 2 of parents' problem definitions  
(i.e., overall relevance of information)*

The overall relevance of information provided in parents' definition of problems was established in two steps. First, by computing the total scores for specificity, operationalization/concreteness and comprehensiveness of information across the sub-dimensions for Dimension 1 (organization of information); and second, by obtaining an average of the three scores (refer to the data capturing and rating sheet for the Problem Definition Question in Appendix L). The raters' level of agreement on the average score was computed and is shown in Table AH5.

Table AH5

*Inter-rater agreement on the overall relevance of information*

Overall relevance of information given in parents' problem definitions	Rater 2	Rater 3
Mean	1.5	1.5
Standard deviation	0.6	0.5
t-test		0.7
p value		<b>0.5</b>

Despite the minor discrepancies in ratings reflected in Tables AH3 and AH4, the raters' scores showed complete agreement on the overall relevance of information given by parents when defining problems in parenting young children with communication disabilities. The findings render the data reliable.

*(iii) Inter-rater agreement in coding overall problem definition*

As described in Table AH1, the two dimensions of problem definition (i.e. *organization* and *relevance* of information) were weighted equally as both were considered critical in facilitating the speech-language therapists' understanding of the problem (D'Zurilla & Nezu, 1999). The overall problem definition score therefore comprised an average of the final scores for the two dimensions. Inter-rater agreement on the final score is shown in Table AH6. There was close agreement between the raters regarding parents' overall problem definition skills.

Table AH6

*Inter-rater agreement on parents' overall problem definition skills*

Parents' overall problem definition skills	Rater 2	Rater 3
Mean	1.8	1.7
Standard deviation	0.7	0.6
t-test		1.69
p value		<b>0.1</b>

*(iv) Intra-rater agreement reliability*

Finally, **to control for practice effects on rating**, the raters recoded the open-ended questions in the two measures (i.e. Problem Orientation Questionnaire and Problem Definition Question) in five audio-recordings that were randomly selected from the initial 10 audio-recordings that were done (Lewis et al., 1991). In total, six items were re-coded as listed in point 3.4.2.5. For each item, findings reflected 100% agreement between each rater's first and second ratings. The findings implied that each rater was consistent in applying her understanding of the problem orientation and definition constructs during initial and final ratings of both measures. The findings supported the reliability of the ratings and credibility of the rating guidelines that were developed for the study.

In view of the findings and the overall marginal differences in values that were significant, it can be *concluded that inter-rater and intra-rater agreement reliability was generally favourable - implying that the data were reliable.*

**Level 4: Functional equivalence of the experimental and control groups**

Both groups were found to be functionally equivalent, thus rendering the data reliable. The analysis and conclusion are discussed in detail in point 4.2.1 in Chapter 4.

### **Level 5: Parents' evaluation of the interviews and training (social validity)**

Parents in the experimental group (n=15) evaluated the training programme at two levels: (a) daily after each training session on Days 1-3, to determine if any changes were required to improve the training (Appendix V), and (b) at the end of the 4-day training, to determine parents' overall evaluation of the training received (Appendix W). Results for each are presented and discussed briefly.

#### **(a) Parents' daily evaluation of the training sessions**

Table AH7 outlines the composite results of parents' daily evaluations for training days 1-3.

Table AH7

*Composite results for parents' daily evaluation of training days 1-3*

<b>Evaluation areas</b>	<b>% Agree</b>	<b>% Unsure</b>	<b>% Disagree</b>
The trainer was well prepared for the training: Day 1-3	100%	-	-
The training was easy to follow: Day 1-3	100%	-	-
I feel comfortable participating in the different training methods, for example, role play; group discussions Days 1-3	100%	-	-
The length of the training was sufficient			
Day 1	79%	14%	7%
Day 2	100%	-	-
Day 3	100%	-	-
The videos and slideshows help me to learn better ways of managing my difficulties: Day 1-3	100%	-	-
There were enough opportunities for me to participate during training : Day 1-3	100%	-	-
I will be able to work on the homework assignments given : Days 1-3	100%	-	-
<b>Overall rating of training</b> (very poor to very good)			
Day 1-3		Very good - 100%	

Participants' ratings of the training received from Days 1-3 were very positive (79%-100%). However, 21% of participants were not happy about the length of training on Day 1 (14% were unsure, whilst 7% disagreed). This finding could be attributed to training commencing 20 minutes later than the scheduled time, as not all participants had arrived on time. The latter resulted in training continuing 20 minutes over the scheduled time, and some participants not having sufficient time to talk about their parenting experiences.

## (b) Parents' overall evaluation of the training programme

The general evaluation questionnaire evaluated parents' assessment of four key factors relating to the training programme: (a) how useful they found the information that was given during training; (b) the impact that training had at three levels: (i) parents orientation to and definition of problems experienced in parenting children with communication disabilities, (ii) parent's descriptions of problems when seeking help in general, and (iii) parents' recommendation of the training programme for other parents who have children with communication disabilities; (c) factors that facilitated and hindered parents' participation in the interviews and training programme, and lastly, (d) parents' suggestions on how the training could have been planned better to facilitate participation.

The findings are as follows:

**(a) *Usefulness of training:*** Overall, all parents found the training useful, with 93% (13) rating it as *very useful* and 7% (1) as *useful*.

**(b) *Impact of training:*** (i) All (100%) parents *strongly agreed* that the training facilitated or strengthened their positive attitude towards parenting their child. In contrast, although 87% (13) *strongly agreed* that the training improved their ability to describe their child's communication difficulties to the speech-language therapist, 13% (2) of parents agreed.

(ii) A similar pattern in results is evident in relation to the training improving parents' skills in describing any problem to help-givers [93% (14) *strongly agreed* and 7% (1) *agreed*]. Although the overall findings are generally very positive, the slightly weaker response from three parents may be due to the limited time that was available during training for all participants to demonstrate their problem definition skills and receive detailed feedback from the researcher.

(iii) It was very encouraging to note that all parents indicated that they would recommend the training to other parents who have children with communication disabilities.

(c) Table AH8 illustrates the *factors that facilitated and hindered parents' participation* in the interviews and training programme. All parents indicated that key factors relating to the information provided, training methods used and training logistics *facilitated* their

participation in the training. Similar results were found with respect to the pre-and-post-training interviews. However, a few parents (13% and 7% respectively) found that having their interviews conducted at the hospital (which they selected to do), and finding childcare *hindered participation*.

Table AH8

*Factors that facilitated and hindered parents' participation*

<b>Factors</b>	<b>Facilitated participation in the study</b>	<b>Hindered participation in the study</b>
<b>Pre-and-Post Training Interviews:</b>		
Researcher paying toward transport costs	100%	
Interviews conducted at home	100%	
Interviews conducted at the hospital	87% (13)	13% (2)
Getting help with child care	93% (14)	7% (1)
The type of questions asked: e.g. easy to understand (facilitated) difficult to understand (hindered)	100%	
The interviewer e.g. easy to talk to (facilitated) difficult to talk to (hindered)	100%	-
<b>Training programme</b>		
Information provided e.g. Relevant (( facilitated) Irrelevant (hindered)	100%	
The programme e.g. Fun and interesting (facilitated) Boring (hindered )	100%	
The teaching methods e.g helped learning/interesting (facilitated) Did not help learning/Boring (hindered)	100%	
Training instructions (easy/difficult to follow)	100%	
<b>Training methods:</b>		
Lectures	100%	
Role playing	100%	
Large group discussions	100%	
Small group discussions	100%	
Videos	100%	
Slideshows	100%	
Homework assignments	100%	
<b>Other training logistics</b>		
The venue	100%	
Researcher paying toward transport costs	100%	
Tea and light snacks	100%	
Number of training sessions	100%	

*(d) Parents' suggestions on how the current training could have been planned to facilitate parents' participation:* Three of the 15 parents listed the following two suggestions: (i) providing assistance with child-care, and (ii) conducting the interviews at the parents' home.

Parents overall evaluation of the training was very positive, thereby supporting the reliability of data collected.

**Overall conclusion:** The five levels of reliability assessment reveal adequate measurement and procedural reliability of the data and data collection processes. This finding augurs well for deriving valid and meaningful interpretations of the data, and final conclusions of the study (Schlosser, 2003; McMillan & Schumacher, 2010; Leedy & Ormrod, 2013).

## Appendix AI

### Procedural consistency in the implementation of pre-and-post training interviews and data capture

Areas assessed	Pre-training	Post-training
Interview process	Rater 1	Rater 1
Interviews commenced with greetings.	4	4
Relevant explanations were provided in accordance with the aims of the pre-and-post training interviews relating to: the purpose of the study, the two interviews and training, informed consent and audio-recordings.	4	4
Instructions for the two questionnaires and problem definition question were provided clearly.	4	4
A sequential order of questioning was followed, commencing with the Biographical Information Questionnaire, followed by the Problem Definition Question, and finally the Problem Orientation Questionnaire.	4	4
The Problem Orientation Questionnaire was presented in font size 14 so parents could easily scan the response alternatives and select their response.	4	4
All response options in the Biographical and Problem Orientation Questionnaires were read out clearly.	4	Not applicable
Parents were given sufficient time to answer all questions.	4	4
Probing was used in accordance with requirements for each questionnaire/question.	4	4
Parents' questions were answered in a non-biased manner.	4	4
Interviews concluded by providing parents with money for transport, and thanking parents.	4	4
Data capture process		
Parents' responses to closed ended questions in the Biographical Questionnaire were recorded correctly	4	Not applicable
Parents' responses to closed ended questions in the Problem Orientation Questionnaire were recorded correctly	4	4
Parents responses to the two open-ended questions in the Problem Orientation Questionnaire were transcribed correctly (checked by the researcher).	4	4
<b>Overall rating</b>	<b>4</b>	<b>4</b>

\*Note: Likert scale rating: 1=poor; 2=satisfactory; 3=good; 4=very good

## Appendix AJ

### Treatment integrity results

Areas evaluated	Rater 1				Mean rating
	Day 1	Day 2	Day 3	Day 4	
<b>(i) Trainer adherence to, competence in and implementation of training</b>					
<b>Trainer's knowledge</b> Demonstrated knowledge and understanding of the concept of problem orientation (DV1)	4	4	4	4	4
Demonstrated knowledge and understanding of the concept of problem definition (DV2)	4	4	4	4	4
<b>Trainer's implementation of training</b>					
Followed training plan with respect to content areas	4	4	4	4	4
Maintained orderly flow of information	4	4	4	4	4
Flexible and responsive to parents' needs without compromising training goals	4	4	4	4	4
Sensitive timing and pacing of content	4	4	4	4	4
Accomplished training session goals	4	4	4	4	4
<b>Teaching skills</b>					
Provided relevant information on the constructs of problem orientation and definition in an easy to understand format	4	4	4	4	4
Explained reasons for recommended behaviour changes (rationale)	4	4	4	4	4
Proficiency in using interactive teaching strategies and tools to facilitate parents' mastery and independent use of problem orientation and definition behaviours	4	4	4	4	4

Areas evaluated	Rater 1				Mean rating
	Day 1	Day 2	Day 3	Day 4	
<b>Clinical skills</b>					
Created a safe and supportive context for learning	4	4	4	4	4
<b>(ii) Participants</b>					
<b>Adherence and participation during training</b>					
Participated actively in the essential components of the training plan, as directed by the trainer	3	4	4	4	3.75
Completed all homework assignment	-	4	4	4	4
Showed interest in the training content	4	4	4	4	4
Attended training session	4	4	4	4	4
<b>Overall rating (mean)</b>	3.93	4	4	4	<b>3.98</b>

\*Note: Likert scale rating: 1 =poor; 2=satisfactory; 3=good; 4= very good

## Appendix AK

### Interpretation of statistically significant results for problem orientation and definition

Table AK1

*Interpretation of statistically significant findings for the experimental and control group parents' orientation to problems*

Dimension of Problem Orientation	Items	p-value Wilcoxin Test	Experimental Group (n=15)		Control Group (n=19)		Effect of training
			Pre-training $\bar{X}$ & interpretation	Post-training $\bar{X}$ & interpretation	Pre-training $\bar{X}$ & interpretation	Post-training $\bar{X}$ & interpretation	
<b>Problem attribution</b>	Perception of the <i>initial cause</i> of the child's communication disability.	0.0005*	$\bar{X}$ =1.80 Moderately negative orientation	$\bar{X}$ =3.66 Largely positive orientation	$\bar{X}$ =2.11 Slightly negative orientation	$\bar{X}$ =2.11 Slightly negative orientation	Positive Large Effect size
	Attribution of <i>blame</i> for causing the communication disability.	0.0313*	$\bar{X}$ =2.86 Slightly positive orientation	$\bar{X}$ =3.80 Largely positive orientation	$\bar{X}$ =3.05 Slightly positive orientation	$\bar{X}$ =3.05 Slightly positive orientation	Positive Medium Effect size
	<i>Effect of the established disability</i> on the child's ability to learn, if given treatment.	0.0156*	$\bar{X}$ =3.20 Moderately positive orientation	$\bar{X}$ =4.00 Positive orientation	$\bar{X}$ =3.63 Largely positive orientation	$\bar{X}$ =3.63 Largely positive orientation	Positive Medium Effect size
	Perception of the <i>maintaining cause</i> of the child's communication disability	0.0002*	$\bar{X}$ =1.73 Moderately negative orientation	$\bar{X}$ =4.00 Positive orientation	$\bar{X}$ =2.42 Slightly negative orientation	$\bar{X}$ =2.42 Slightly negative orientation	Positive Large Effect size
<b>Problem appraisal</b>	Perception of the child's communication disability as a <i>threat or challenge</i> .	0.0010*	$\bar{X}$ =2.86 Slightly positive orientation	$\bar{X}$ =4.00 Positive orientation	$\bar{X}$ =2.78 Slightly positive orientation	$\bar{X}$ =2.52 Slightly negative orientation	Positive Large Effect size
<b>Personal control</b>	Confidence in asking family and friends for help.	0.0156*	$\bar{X}$ =3.20 Moderately positive orientation	$\bar{X}$ =3.86 Largely positive orientation	$\bar{X}$ =2.89 Slightly positive orientation	$\bar{X}$ =3.00 Slightly positive orientation	Positive Medium Effect size

Note: \*statistical significance at 5% confidence level

Scoring: 1=negative orientation

4=positive orientation

Table AK2

*Interpretation of statistically significant findings for the experimental and control group parents' definition of problems*

Dimensions of Problem Definition	Item	p-value Wilcoxon Test	Experimental Group (n=15)		Control Group (n=19)		Effect of training
			Pre-training $\bar{X}$ & interpretation	Post-training $\bar{X}$ & interpretation	Pre-training $\bar{X}$ & interpretation	Post-training $\bar{X}$ & interpretation	
<b>Dimension 1 Overall Organization of information</b>	<b>Overall Organization of information</b> <i>Sub-dimension 1:</i> What is the problem, to whom & why? <i>Sub-dimension 2:</i> What is the desired outcome, for whom and why? <i>Sub-dimension 3:</i> What obstacles make it difficult for the parent and/or child to achieve the desired outcomes?	0.0005*	$\bar{X}$ =1.87 poor	$\bar{X}$ =3.33 moderately good	$\bar{X}$ =2.11 moderately poor	$\bar{X}$ =2.11 moderately poor	Positive Large Effect size
<b>Dimension 2 Overall Relevance of Information (specificity, concreteness and comprehensiveness of information)</b>	Sub-dimension 1: specificity of information	0.0001*	$\bar{X}$ =1.60 poor	$\bar{X}$ =3.18 moderately good	$\bar{X}$ =1.68 poor	$\bar{X}$ =1.68 poor	Positive Large Effect size
	Sub-dimension 2: concreteness of information	0.0001*	$\bar{X}$ =1.49 poor	$\bar{X}$ =3.16 moderately good	$\bar{X}$ =1.63 poor	$\bar{X}$ =1.63 poor	Positive Large Effect size
	Sub-dimension 3: comprehensiveness of information	0.0001*	$\bar{X}$ =1.48 low	$\bar{X}$ =3.07 moderately high	$\bar{X}$ =1.48 low	$\bar{X}$ =1.48 low	Positive Large effect size
	<b>Overall Relevance of Information</b> (average score of sub-dimensions 1-3)	0.0001*	$\bar{X}$ =1.51 low	$\bar{X}$ =3.15 moderately high	$\bar{X}$ =1.57 low	$\bar{X}$ =1.57 low	Positive Large effect size
<b>Final Problem Definition</b>	<b>Overall Organization and Relevance of information</b> (average score)	<b>0.0001*</b>	$\bar{X}$ =1.70 poor	$\bar{X}$ =3.27 moderately good	$\bar{X}$ =1.85 poor	$\bar{X}$ =1.85 poor	<b>Positive Large Effect size</b>

Note: \*statistical significance at 5% confidence level

Scoring: 1= poor problem definition skills

4 = good problem definition skills

Table AK3

*Implications of statistically significant results on parents' problem orientations pre-and-post-training*

Dimension of Problem Orientation	Items	Pre-training $\bar{X}$ Interpretation & implication for help seeking in ECCI Experimental and Control group (n=34)		Post-training $\bar{X}$ Interpretation & implication for help seeking in ECCI Experimental group (n=15)      Control group (n=19)			
		Problem attribution	Perception of the <i>initial cause</i> of the child's communication disability.	$\bar{X}$ =1.80 to 2.11 Slightly to moderately negative orientation	Slightly to moderately negative effect on help seeking. Parent support strongly recommended.	$\bar{X}$ =3.66 Largely positive orientation	Largely positive effect on help seeking. Parent support in one or two areas recommended.
Attribution of <i>blame</i> for causing the communication disability.	$\bar{X}$ =2.86 to 3.05 Slightly positive orientation		Slightly positive effect on help seeking. Parent support strongly recommended.	$\bar{X}$ =3.80 Largely positive orientation	Largely positive effect on help seeking. Parent support in one or two areas recommended	$\bar{X}$ =3.05 Slightly positive orientation	Slightly positive effect on help seeking. Parent support strongly recommended.
<i>Effect of the established disability</i> on the child's ability to learn, if given treatment.	$\bar{X}$ =3.20 to 3.63 Moderately to largely positive orientation		Moderately to largely positive effect on help seeking. Parent support strongly recommended.	$\bar{X}$ =4.00 Positive orientation	Very positive effect on help seeking	$\bar{X}$ =3.63 Largely positive orientation	Largely positive effect on help seeking. Parent support strongly recommended
Perception of the <i>maintaining cause</i> of the child's communication disability	$\bar{X}$ =1.73 to 2.42 Slightly to moderately negative orientation		Slightly to moderately negative effect on help seeking. Parent support strongly recommended.	$\bar{X}$ =4.00 Positive orientation	Very positive effect on help seeking	$\bar{X}$ =2.42 Slightly negative orientation	Slightly negative effect on help seeking. Parent support strongly recommended

Dimension of Problem Orientation	Items	Pre-training $\bar{X}$ Interpretation & implication for help seeking in ECCI Experimental and Control group (n=34)		Post-training $\bar{X}$ Interpretation & implication for help seeking in ECCI			
				Experimental group (n=15)		Control group (n=19)	
Problem appraisal	Perception of the child's communication disability as a <i>threat or challenge</i> .	$\bar{X}$ =2.78 to 2.86 Slightly positive orientation	Slightly positive effect on help seeking. Parent support strongly recommended.	$\bar{X}$ =4.00 Positive orientation	Very positive effect on help seeking	$\bar{X}$ =2.52 Slightly negative orientation	Slightly negative effect on help seeking. Parent support strongly recommended
Personal control	Confidence in asking family and friends for help.	$\bar{X}$ =2.89 to 3.20 Moderately positive orientation	Moderately positive effect on help seeking. Parent support strongly recommended.	$\bar{X}$ =3.86 Largely positive orientation	Largely positive effect on help seeking. Parent support in one or two areas recommended	$\bar{X}$ =3.00 Slightly positive orientation	Slightly positive effect on help seeking. Parent support strongly recommended.

Note. Scoring: 1=negative orientation      4=positive orientation

Table AK4

Overview of interpretations at pre-and-post-training for statistically significant results on parents' problem definition

Dimensions of Problem Definition	Item	Pre-training $\bar{X}$ & interpretation Experimental & Control Group (n=34)	Post-training $\bar{X}$ & interpretation Experimental Group (n=15)	Control group (n=19)
Dimension 1 Overall Organization of information	<p><i>Sub-dimension 1:</i> What is the problem, to whom &amp; why?</p> <p><i>Sub-dimension 2:</i> What is the desired outcome, for whom and why?</p> <p><i>Sub-dimension 3:</i> What obstacles make it difficult for the parent and/or child to achieve the desired outcomes?</p>	$\bar{X}$ =1.87 to 2.11  poor to moderately poor organization of information	$\bar{X}$ =3.33 moderately good	$\bar{X}$ =2.11 moderately poor
Dimension 2 Overall Relevance of Information (specificity, concreteness)	Sub-dimension 1: specificity of information	$\bar{X}$ =1.60 to 1.68 poor	$\bar{X}$ =3.18 moderately good	$\bar{X}$ =1.68 poor
	Sub-dimension 2: concreteness of information	$\bar{X}$ =1.49 to 1.63 poor	$\bar{X}$ =3.16 moderately good	$\bar{X}$ =1.63 poor
	Sub-dimension 3: comprehensiveness of information	$\bar{X}$ =1.48 low	$\bar{X}$ =3.07 moderately high	$\bar{X}$ =1.48 low
	<b>Overall Relevance of Information</b> (average score of sub-dimensions 1-3)	$\bar{X}$ =1.51 to 1.57 Low relevance	$\bar{X}$ =3.15 moderately high relevance	$\bar{X}$ =1.57 low
Final Problem Definition	<b>Overall Organization and Relevance of information (average score)</b>	$\bar{X}$ =1.70 to 1.85 <b>Poor problem definition skills</b>	$\bar{X}$ =3.27 <b>Moderately good problem definition skills</b>	$\bar{X}$ =1.85 <b>poor</b>
	<b>Implication for ECCI planning</b>	Information is poorly organized, and of limited relevance. Therapist has a generally poor understanding of the problem and needs. Relevant ECCI planning is facilitated to a limited extent.	Information is largely organized, and relevant. Therapist has a generally good understanding of the problem and needs. Relevant ECCI planning is facilitated to a large extent.	Information is poorly organized, and of limited relevance. Therapist has a generally poor understanding of the problem and needs. Relevant ECCI planning is facilitated to a limited extent.

Note. Scoring: 1= poor problem definition      4= good problem definition

## Appendix AL

### Guidelines for speech-language therapists to gather relevant information for successful ECCI planning

The following guidelines provide a systematic approach to gather relevant information during the case history interview with parents of children with disabilities. The questions facilitate the collaborative problem solving process that is crucial for effective, sustainable and versatile intervention planning.

For parent information to be <b>relevant for intervention planning</b> , it must be <b>specific, concrete and comprehensive</b> as follows:			
<b>Three steps to a systematic approach</b> to identifying problems and needs: <i>Ask the following questions</i>	<b>Specific to any of the following</b>	<b>Supported with examples from their daily routines and activities (concrete)</b>	<b>Contextualized from onset and development to current status (comprehensive)</b>
<b>1. What is the problem?</b>	(i) <b>Child:</b> Body structure & functioning (e.g. Activity/activity limitations Participation restrictions	e.g my child has cerebral palsy. He cannot talk clearly.	The description needs to outline the (i) <b>onset</b> , (ii) <b>progression</b> , and (iii) <b>current status</b> of the problem.
<b>To whom is it a problem?</b>	(ii) <b>Associated problems:</b> <b>Environmental factors</b> Physical Social Economic Cultural Other <b>Personal factors:</b> Parents' Health other		Descriptions must relate to the parenting tasks implemented in the role of caregiver.  Descriptions need to explain expectations (derived from the family's socio-behavioural values and beliefs.
<b>Why is it a problem?</b>	Effect on family's everyday routines and activities at home, school, work, etc.	e.g I don't know what he wants when he cries.	The parent should acknowledge if there are any gaps in the information e.g. results from other assessments; poor knowledge about something (e.g. developmental milestones)



For parent information to be **relevant for intervention planning**, it must be **specific, concrete and comprehensive** as follows:

<b>Three steps to a systematic approach to identifying problems and needs:</b> <i>Ask the following questions</i>	<b>Specific to any of the following</b>	<b>Supported with examples from their daily routines and activities (concrete)</b>	<b>Contextualized from onset and development to current status (comprehensive)</b>
	- education - legislation  <b>Personal:</b> Parents' lack of knowledge, skills, etc.		

**Parents' needs must be analysed further as follows to facilitate effective intervention planning:**

- Nature of intervention required (child/parent/family focused)
- Are the needs realistic?
- Are the needs attainable?
- To what extent will the needs identified resolve the problems described? (e.g. fully/partially)