

# CHAPTER 1

## ORIENTATION

### 1.1 INTRODUCTION

This chapter provides an orientation to the research and includes background information, the purpose of the research as well as a graphic representation of the chapter outlines.

### 1.2 BACKGROUND

When looking at the focus of developing countries regarding service delivery to children with severe disabilities (CSDs), it is clear that the services that had been established in developing countries in the past share some common characteristics.

Since the birth of South Africa's new democracy in 1994, different attempts had been made to create opportunities for everyone - not only in the educational and vocational sectors, but also in health. Although some progress has been made, particularly regarding policy development and legislation, some pertinent challenges still need to be addressed, one of which is disability. It is evident that there is a high incidence of disability in South Africa. It is estimated that 5 - 12% of South Africans are moderately to severely disabled (NPA, 1999). Of South Africa's total population of 40 million, 73% are women and children (Government Gazette no 17910, 1997) placing them at a higher risk for disability. More than 80% of black children with a disability live in extreme poverty and have poor access to appropriate health facilities or early childhood

developmental opportunities (NPA, 1999). In the sphere of individuals with severe disabilities, a particularly vulnerable and neglected group is that with communication and intellectual impairments due to their inability to articulate their needs, feelings and rights (Thorburn & Marfo, 1990). A study conducted in schools for children with cognitive impairment in and around Pretoria (South Africa) indicated that 39% of these children were using less than 15 intelligible words (Bornman & Alant, 1997). This percentage is significantly higher than that of comparable international studies such as the 2,4% reported in North Dakota (Burd, Hammes, Bornhoeft & Fisher, 1988) and 6% in rural areas in Washington state (Matas, Mathy-Laikko, Beukelman & Legresley, 1985). There are different reasons for this, including the fact that persons with severe disabilities in South Africa are not exposed to Augmentative and Alternative Communication (AAC) strategies as it is still a relatively new field of expertise in our country. Internationally it is also reported that programmes to specifically address these communication needs by equipping these children with the necessary skills to interact, are limited (Werner, 1987, WHO, 1995).

Apart from the high incidence of disability in developing countries, these individuals also share commonalties in terms of services the offered. It is well-documented in the literature that people with severe disabilities receive less education and vocational training, and are often unemployed, resulting in poverty (Lundgren-Lindquist & Nordholm, 1993). The aura of charity still pervades many of the services offered to help and rarely are the persons with disabilities given the chance to help themselves (McConkey, 1996). Due to long held low expectations of people with severe disabilities, they are often excluded from any leadership position or from any planning and decision-making in their

communities, resulting in a lack of representation of their needs.

In addition, very few professionals in South Africa are trained in AAC implementation, and thus able to provide AAC intervention to people in need. This is due to the fact that communication intervention for CSDs has not been a priority, and that international sanctions limited South Africa's participation in the international AAC field until the early nineties. In addition, the majority of services provided by professionals are located in a few large cities making it inaccessible to the rural population, leading to services being provided to less than three percent of disabled people in need (Thorburn & Marfo, 1990). Professionals also tend to work in isolation, with minimal integration between services, which led many people to believe that service provision to disabled people was too complicated to be administered by persons other than professionals. It was thought that any other form of rehabilitation would be ineffective (Thorburn & Marfo, 1990).

At present, much of the discourse in the health and rehabilitation fields revolve around the way to address issues related to disability and the lack of manpower within the resources of the developing world. One of the possible solutions might be the fact that professionals began to realise the importance of teamwork (O'Toole, 1988). This not only reduces the duplication of services, it also addresses the fragmentation that currently exists amongst different service providers. The sharing of information and the planning of intervention will enable parents, professionals and all persons involved with the disabled child to work towards a common goal (McConachie & Pennington, 1997). Consequently, when accepting the primary health care philosophy, one has to acknowledge the fact that

rehabilitation is too important to be left only to the professionals. Communities have to be made aware of persons with disabilities in their midst and of what can be done to assist them in becoming more active participating members of society (McConkey, 1996). Training therefore needs to be conducted at all levels and should include community leaders, professionals, primary level workers, family members of persons with disabilities, and the persons with disabilities themselves. Primary caregivers should therefore receive support from professionals so that they can make knowledgeable and informed choices regarding their child's rehabilitation.

Added to this, it should be realised that the available Western materials are not applicable to the African context. Thus, when attempting to train individuals regarding disability and communication issues, appropriate materials and methods for assessment and intervention that are ecologically valid, need to be developed. In an UNESCO declaration (in Thorburn & Marfo, 1990) the importance of culturally sensitive materials that are suitable to a specific context are highlighted.

In summary it can thus be said that CSDs and their primary caregivers are a neglected group with few resources.

On the positive side, CSDs and their primary caregivers often have contact with community health nurses as primary health care clinics are relatively easily accessible to all South Africans, even those living in rural and remote areas. Furthermore, they often remain the only professionals who provide support and assistance to caregivers of pre-school children. It is therefore clear that these health care workers need to be equipped with the necessary skills and

expertise to assist caregivers in dealing with their children with severe disabilities.

This led to the development of the Beginning Communication Intervention Protocol (BCIP). This is a training programme that is aimed at equipping community health nurses with the knowledge and skills (through multiskilling) to function as true transdisciplinary professionals. It aims at defining beginning communication skills in terms of various communication means (both aided and unaided), communication functions (e.g. requesting help, requesting assistance, protesting, etc.), increasing communication partners as well as the creation of deliberate communication opportunities. The BCIP thus equips the community health nurse to provide training and support to the primary caregivers of CSDs, so that the rehabilitation process can begin. This is in strong contrast to the way in which services are currently being delivered, namely referral to large centres, with little or no compliance (for a number of reasons, e.g. lack of transport, financial difficulties, insensitivity to culture and beliefs, etc.) and little or no follow-up of these individuals.

The aim of this study is therefore to develop and apply a communication intervention protocol aimed at facilitating beginning communication skills (e.g. choice-making, turn-taking, labelling, initiating, drawing attention to self, requesting help, requesting more, rejecting, commenting and indicating humour and surprise) between primary caregivers and CSDs. This protocol is intended for use by community health nurses who work in primary health care clinics in the training of caregivers (parents) to interact with their children.

### 1.3 CHAPTER OUTLINES

The research will be presented in seven chapters. Chapter 1 provides a basic orientation and motivation for the study as well as an outline of the chapters.

In Chapter 2 the concept “transdisciplinary training” is discussed by focusing on it’s relevance to children with severe disabilities (CSDs). This discussion continues by placing transdisciplinary services within the primary health care (PHC) domain, highlighting three important aspects namely prevention, participation and protection. This chapter concludes by providing a communication orientation to transdisciplinary training in which two approaches, namely multiskilling and collaboration are highlighted. The roles of the main participants in this process, namely community health nurses, primary caregivers of CSDs, and CSDs themselves, are highlighted.

The concept “*communication*” is the focus of Chapter 3. It describes the main elements of a beginning communication protocol (the BCIP) by highlighting the importance of including communication means, functions, partners and the deliberate creation of communication opportunities. It also includes an outline of the training programmes / packages that currently exist, and describes the components that should be included in a programme to ensure efficacy. This chapter is concluded a brief discussion of important elements of adult training.

The methodology is set out in Chapter 4. This includes a description of the aims and objectives, the research design, pilot study and the main study, highlighting the participant selection procedure and a description of the community health nurses who were included, the equipment and materials

used, as well as the data collection and analysis procedures.

Chapter 5 presents an overview of the results obtained. Emphasis is placed on results that yielded the primary outcomes of the study (namely knowledge and skills). This is followed by a description of secondary outcomes (attitudes, job satisfaction, and motivation to work with CSDs and their primary caregivers as well as type of services provided to this population). Finally, a general evaluation of the training (in terms of methodology and content) is provided.

This is followed by a discussion of the results, which is the focus of Chapter 6. Outcomes of the BCIP training were integrated with the various nursing tasks required from community health nurses working with CSDs and their primary caregivers. The change noted in knowledge and skills is highlighted and the role of the BCIP in facilitating this process is explored.

In Chapter 7 the conclusions and implications of the study are presented, together with a critical evaluation of the study and recommendations for future research.

#### **1.4 SUMMARY**

This chapter provided the motivation for the study by describing the background information that led to its development as well as a description of the research purpose. It concludes by providing an outline for the different chapters by which the aims of the study will be realised.