

## **CHAPTER 2**

# **TRANSDISCIPLINARY TRAINING, PRIMARY HEALTH CARE AND COMMUNICATION INTERVENTION**

### **2.1 INTRODUCTION**

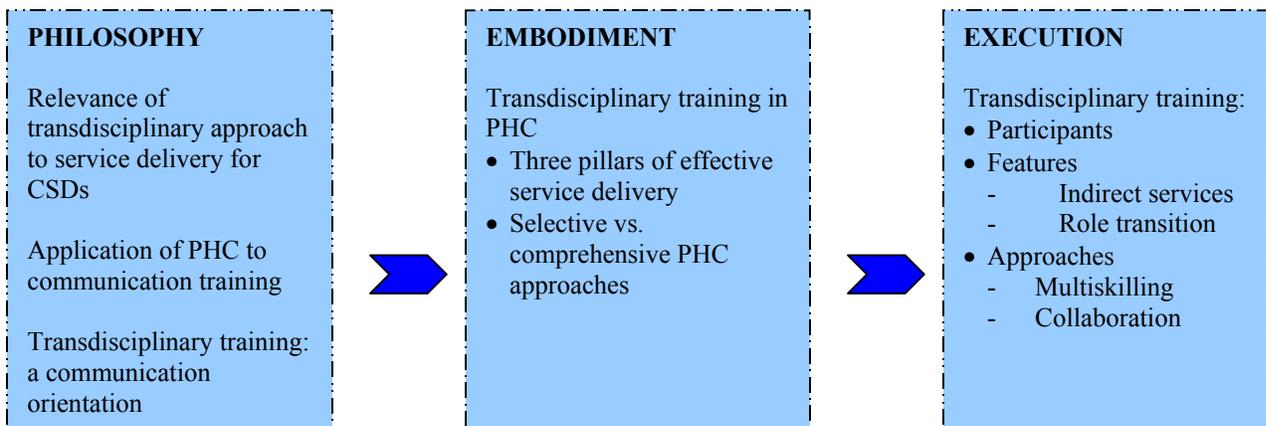
Meeting the diverse needs of children with severe disabilities within the primary health care (PHC) sphere is a complex task that cannot be effectively addressed by one profession (Bailey, Simeonsson, Yoder & Huntington, 1990). However, by training existing personnel at this level (e.g. community health care nurses) to function as transdisciplinary professionals, service delivery to this traditionally neglected group of individuals becomes viable. This chapter discusses a transdisciplinary approach to service delivery and its relevance for CSDs and then links transdisciplinary training within a PHC context and communication training to this population. The chapter continues by describing how the principles of PHC can be applied to a transdisciplinary communication-focused training programme. The features of transdisciplinary training (i.e. role transition as a process relating to role release where professionals cross traditional professional boundaries and continuous development of personnel) as well as the specific approaches that were used to obtain this (i.e. multiskilling and collaboration) are highlighted.

Traditionally a medical approach to service delivery was followed, which defined health as absence of disease (Slajmer-Japeli, 1995). This made way for the community development or social approach that is currently used and which defines health as a human condition which is the result of social, economic and political development (Thomas, 1999a). This implies that one professional is not equipped to address all the health needs of an individual effectively. In addition, a lack of trained professionals who are equipped to provide services to all in need, particularly those in rural and remote areas, exists (Bortz, Jardine &

Tshule, 1996; Moodley, Louw & Hugo, 2001). These factors highlight the importance of transdisciplinary functioning of professionals, which emphasises collaboration and the transfer of information, knowledge and skills across discipline boundaries (Zangari & Wasson, 1997). Professionals are required to share knowledge so that they become proficient in areas other than their primary specialities – a concept known as role transition which includes role extension, role enrichment, role expansion, role exchange and finally role release (Orelove & Sobsey, 1996; Parker, 1994).

A summary of the contents of Chapter 2 is presented graphically in Figure 2.1

**Figure 2.1 Transdisciplinary training, PHC and communication intervention**



## **2.2 TRANSDISCIPLINARY APPROACH TO SERVICE DELIVERY: RELEVANCE TO CSD**

Defining “*children with severe disabilities*” poses serious problems as it brings to mind a vast number of images, ranging from a Down’s Syndrome to a spastic quadriplegic person. Often these individuals cannot easily make themselves understood. They may be passive – either partially or completely, which may be the result of their level of cognitive functioning or due to the fact that all their needs are anticipated and met, leading to learned helplessness (Reichle, 1991). They may exhibit challenging behaviour (Durand, 1990). They may seem to understand more than they are able to communicate.

They may not be motivated to communicate, as they may not have anything to communicate about or anybody to communicate with. These images are all relevant, as are many others. Apart from the different aetiologies leading to disability, it comes from all age, socio-economic and ethnic groups.

One approach in defining this population is by defining their characteristics and examining the different areas of involvement, e.g. *“A severely disabled child is one who, because of the intensity of physical, mental or emotional problems, or a combination of such problems, needs educational, social, psychological and medical services beyond those which have been offered by traditional regular and special education programs, in order to maximise his full potential for useful and meaningful participation in society and for self-fulfilment. Such children include those classified as seriously emotionally disturbed (schizophrenic and autistic), profoundly and severely mentally retarded, and those with two or more serious handicapping conditions such as the mentally retarded deaf, and the mentally retarded blind”* (US Department of Education in Sailor & Guess, 1983, p.5). From this definition it is thus clear that the combination of physical, cognitive, communicative, sensory and/or socio-emotional dependence on support, result in far-reaching and diverse rehabilitative, educational and medical needs of this population. Therefore, CSDs present an immense challenge to all professionals working with them (Orelove & Sobsey, 1996).

It is thus evident from the above that one single profession is not equipped to provide services to CSDs and their families. Expertise from a number of different professions are required, e.g. OT, SLP, PT, nursing, teachers, psychologists etc. Professionals consequently began to recognise the need for sharing expertise across traditional disciplinary borders, for assimilating knowledge from other disciplines and for collaboration, resulting in a transdisciplinary approach to service delivery (Atkins-Burnett & Allen-Meares, 2000; Orelove and Sobsey, 1996; Zangari & Wasson, 1997).

The ability of professionals to function in a transdisciplinary manner is thus not only beneficial to meeting the diverse needs of CSDs, but supports one of the principles

underlying South Africa's National Health System, namely primary health care. The Alma Ata declaration identified PHC as "... *essential health care made universally accessible to individuals and families in the community by means acceptable to them, through their full participation and at a cost that the community and country can afford*" (WHO/UNICEF in Rifkin 1986:240). Therefore, in order to meet the needs of as large a number of people as possible in a culturally appropriate, cost effective way, all possible resources must be utilised (House, McAlister & Naidoo, 1990; Stanhope, 1995). Consequently, professionals began to realise that primary caregiver involvement is central to service delivery, that a high degree of collaboration and joint decision making between primary caregivers and professionals should be established, and that the cross training of professionals and para-professionals in providing services to CSDs should be highlighted (Chapman & Ware, 1999; O'Toole, 1988). These three aspects form the basis of a transdisciplinary approach to service delivery— an approach that not only reduces the duplication of services but one that also addresses the fragmentation and duplication that currently exists amongst different service providers. The transdisciplinary approach is therefore closely linked with PHC as it becomes meaningful within a more comprehensive model of service delivery.

### **2.3 TRANSDISCIPLINARY SERVICE DELIVERY WITHIN PHC**

PHC can be viewed as an approach to health care – it is not only seen as the first level of care but rather as a reorientation of the health care system from its present concentration on late stage, high technology hospital services to community and preventive services (Willis, Biggins & Donovan., 1999). The WHO states that PHC should incorporate the following principles (Thomas, 1999b; McGivern, 1995; Willis *et al.*, 1999):

- Build self-reliance at a personal and community level
- Support community participation in the development of health care programmes
- Collaborate at an intersectoral level to establish environments that are supportive to health

- Integrate health services to facilitate continuity of care and efficiency in resource use
- Provide special attention to high risk and vulnerable groups (e.g. CSDs), as a precondition for equity in health outcomes and health care processes
- Use appropriate technology (McLaren, Philpott & Hlophe, 1997)

PHC is thus seen as the vehicle by which the WHO is attempting to reach the principles of the *Health for All by the Year 2000* document which includes each individual's right to health, equity in health, community participation, intersectoral collaboration and health promotion (Lockhart, 1999; Willis, *et al.*, 1999). PHC is also the underlying philosophy for the restructuring of the South African health system (Department of Health, 1999). When looking at both the principles outlined in PHC and the *Health for All by the Year 2000* document a few interesting trends are seen. Firstly, it highlights community participation, accessibility of services, and the importance of the environment in relation to the health of individuals and communities (Thomas, 1999a). Secondly, it embodies the spirit of partnerships, requiring collaboration and consensus building not only amongst professionals, but also between professionals and communities (Bjäräs, Haglund & Rifkin, 1991; Werner, 1987). Thirdly, it specifically mentions the poor and disenfranchised members of communities, emphasising equity of service delivery (Thomas, 1999a). The emphasis is on self-care, implying that individuals have to be educated to make knowledgeable decisions about their own health and care (Thomas, 1999b). Finally, the preventive rather than the curative end of the health care continuum is advocated (Sameroff & Fiese, 2000).

When viewing PHC within a rural health care system additional factors come to the forefront (Thobaben & Biteman, 1999). Five important aspects related to the training of CSDs and their primary caregivers in PHC were identified. These aspects and their application to communication training are discussed in Table 2.1.

**Table 2.1 PHC aspects as applied to communication training of CSD**

PHC aspect	Application to communication training
<p><b>Community-based Rehabilitation (CBR)</b> Focus of rehabilitation shifts from segregation to community integration (Bradley &amp; Knoll, 1995; Murray, 1980). Should include:</p> <ul style="list-style-type: none"> <li>• Community participation</li> <li>• Appropriate technology</li> <li>• Specific type of service delivery</li> </ul>	<ul style="list-style-type: none"> <li>• Strong focus on collaboration, where CSDs and their primary caregivers are seen as partners (Griffel, 1991; Kisanji, 1995).</li> <li>• Equip community health nurses to conduct health talks to increase the community's knowledge about disability. They will also train primary caregivers of CSDs to enable them to take greater responsibility for their own child's development (Reynolds, Mavrogenes, Bezruczko &amp; Hagemann, 1996).</li> <li>• Use of everyday objects (spoon, cup, plate, etc.) as well as photographs that can be obtained from magazines, PCS symbols that can be drawn and gestures of these objects and pictures. Familiar objects enhance learning of CSDs (Beukelman &amp; Mirenda, 1998; Piché &amp; Reichle, 1991).</li> <li>• Inclusion of appropriate technology, namely a relatively inexpensive digital speaker with four options, which is appropriate to the multilingual South African context as any language can be recorded (Bornman, Alant &amp; Meiring, 2001). In addition, digital speakers are also gender appropriate (as a boy or a girl's voice can be recorded) and age appropriate (younger versus older voice).</li> <li>• Skill orientated training so that community health nurses and primary caregivers know where to start the service delivery process and what to do. It is also locally relevant using ADL as opposed to the more frequently used play-based programmes.</li> </ul>
<p><b>Equity</b> Address needs of previously disadvantaged groups, e.g. CSDs and their primary caregivers, particularly those in rural areas.</p>	<ul style="list-style-type: none"> <li>• Access to services during the critical 0 – 5 years of development (Dworkin, 2000) is limited for CSDs living in rural areas. Due to misconceptions and negative attitudes of the community at large, they are frequently hidden from society. Service delivery to CSDs should start as early as possible to enhance growth and development (Meisels, 1992).</li> </ul>
<p><b>Accessibility</b> The RSA government is attempting to provide a clinic within a five km. radius of every South African (Department of Health, 1999).</p>	<ul style="list-style-type: none"> <li>• Community health clinics are often the only centres in rural areas where professional services are available to CSDs, and therefore community health nurses should be the target professionals for providing communication training to CSD and their primary caregivers at this level.</li> </ul>
<p><b>Environment and availability</b> Existence of essential services and the necessary personnel to provide these essential services to all South Africans, particularly those in rural / remote areas.</p>	<ul style="list-style-type: none"> <li>• High incidence of disability in rural areas, as 53% of the South African population live in rural areas (Government Gazette, 17910, 1997) and 80% of black CSDs live in extreme poverty and have poor access to appropriate health facilities (NPA, 1999). A communication training programme should therefore keep this population in mind.</li> </ul>
<p><b>Acceptability / Social utility</b> Services should be congruent with values, beliefs and customs of the target population (Schubert, Hitchcock &amp; Thomas, 1999).</p>	<ul style="list-style-type: none"> <li>• Ensure cultural sensitivity and relevance. Community health nurses are often from the same community as the ones they serve, heightening their awareness and understanding of cultural factors in health and disability issues (Clark, 1996).</li> </ul>

From the above discussion it is clear that the provision of services (particularly communication training) to CSDs and their primary caregivers within a PHC context is a

challenging task. Professionals require knowledge and skills that move beyond the boundaries of their traditional roles and they need to collaborate more effectively with professionals, family members (e.g. primary caregivers) and the community at large.

### **2.3.1. The three pillars on which effective PHC service delivery rests**

In viewing sustainable service delivery to rural CSDs and their primary caregivers within the PHC sphere, three concepts form the pillars on which sustainable service delivery rests, namely prevention, participation and protection. Each of these aspects will now be described in more detail.

#### **2.3.1.1 Prevention**

According to the Integrated National Disability Strategy (INDS) (1997) prevention is one of the cornerstones of any disability policy as the majority of disabilities are preventable. Orem (1995) noted that prevention requires knowledge of specific interferences with normal health structure and functioning at various stages in an individual's life in particular environments.

The South African Department of Health (1998) has developed a set of objectives to ensure disability prevention. These objectives are generic and pertain to prevention at all three levels. This includes stronger collaboration and co-operation amongst various government departments and communities, the encouragement of greater involvement by DPOs and more community interest in disability prevention, stronger teamwork amongst members of the rehabilitation team, as well as the development of legislation to protect and promote the rights of all citizens (Department of Health, 1998). All of this will be done in accordance with a PHC approach.

**i.) Primary prevention**

Primary prevention encompasses health promotion and disease prevention (Hitchcock, 1999; Stokes, 1997). It identifies action taken to prevent the occurrence of health problems in families, by taking measures to alter risk factors before the disease begins (Orem, 1995). It also refers to the prevention of accidents which may cause impairments and disabilities (INDS, 1997). When looking at disability, primary prevention refers to activities to intervene in the course of a disease so that a disability does not occur (Gilien, 1999). According to the INDS (1997) the major policy objectives to reach this goal are the promotion of a healthy lifestyle in the home, school, and vocational arenas as well as protective measures (e.g. immunisations, protection against accidents, etc). One of the major nursing activities in prevention is “*anticipatory guidance*”(Hitchcock, 1999). This includes obtaining a health history, a physical examination, measurements, sensory screening, developmental and behavioural monitoring, immunisation and age specific counselling (Dworkin, 2000; Solomon, Clougherty, Shaffer, Hofkosh & Edwards, 1994). In primary health care settings, this is often done by offering primary caregivers guidance and support in promoting their child’s development (Dworkin, 2000).

A communication training programme should therefore explain the concepts “*disability*” and “*communication*” to community health nurses, who, in turn can explain it to primary caregivers. This anticipatory guidance will enable primary caregivers to better monitor their child’s progress. In addition, primary prevention can be enhanced by making community health nurses aware of peri-natal and environmental factors that can cause disability.

**ii.) Secondary prevention**

Secondary prevention is appropriate after the onset of the impairment or disability (Orem, 1995) and is directed at the early recognition of impairments and disability followed by treatment (Gilien, 1999; Stokes, 1992). This would also include screening tests (Hitchcock, 1999). Secondary prevention may result in a cure, a slower rate of

progression of the impairment or the prevention of complications (INDS, 1997). The INDS (1997) hopes to achieve this by decreasing poverty, avoiding violence, improving health services (e.g. immunisations, mother-and-child care, family planning, genetic counselling, etc.) reducing environmental accidents and monitoring disease.

A communication training programme that is focused at this level of prevention is required. This programme should adhere to the following principles:

- Equipment of community health nurses with the knowledge and skills to provide services to CSDs and their primary caregivers at a PHC level which can be achieved through multiskilling (Section 2.4.3).
- Comprehensiveness to facilitate close collaboration between primary caregivers and community health nurses and address issues related to disability and communication (Kaplan-Sanoff, Parker & Zuckerman, 1991).
- Continuity of services to ensure that CSDs can be kept at home and be stimulated by their primary caregivers after having been trained by community health nurses.
- Training of community health nurses to refer primary caregivers to other possible resources when necessary, e.g. social services (information on disability grants), genetic counselling (family planning), occupational therapy (seating and mobility), etc. (Eggbeer, 1995).
- Provision of information and modelling of appropriate behaviour to provide primary caregivers with relevant information enabling them to make appropriate and knowledgeable decision about their child's rehabilitation (Freeman & Heinrich, 1981; Roberts, Rule & Innocenti, 1998).

### **iii.) Tertiary prevention**

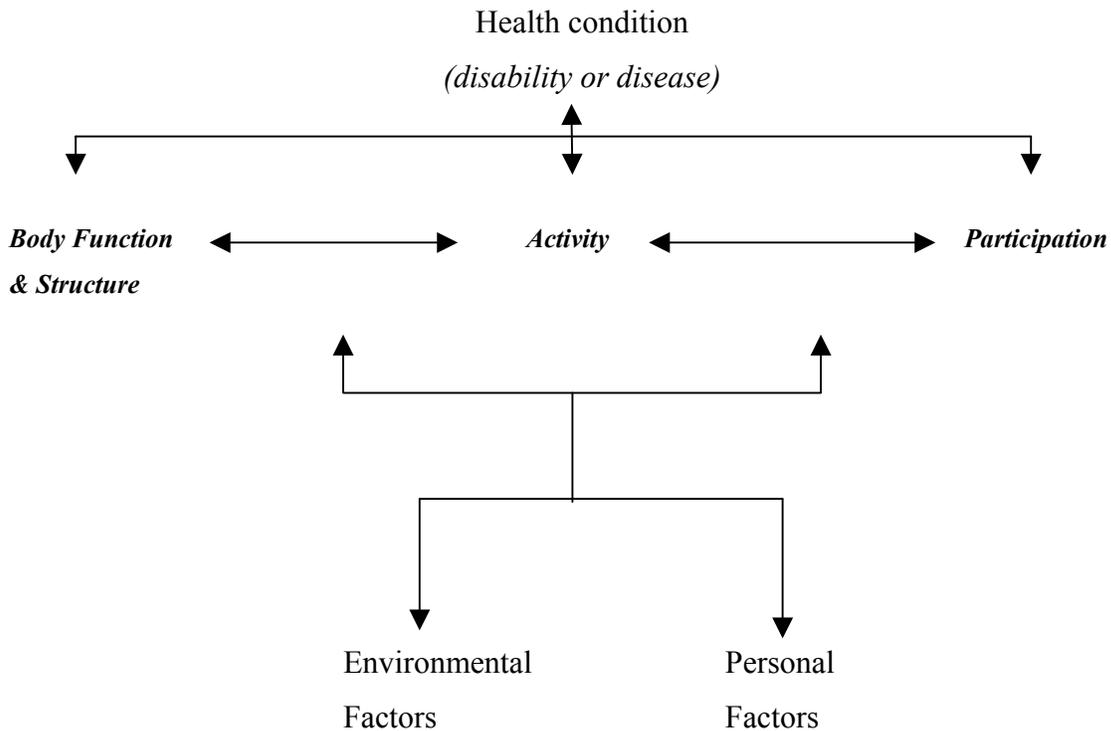
In the past, resources were channelled to tertiary prevention despite indications that a focus on the other two levels of prevention is required (Stokes, 1997). Tertiary prevention has to do with the rehabilitative level of health care (treatment) (Hitchcock, 1999; Orem,

1995). For disability it would refer to activities aimed at limiting the disability or associated problems (Gilien, 1999) and preventing complications (Orem, 1995). As the focus of this study is not on this level, it will not be discussed further.

### **2.3.1.2 Participation**

In 1980 the WHO published the International Classification of Impairment, Disability and Handicap (ICIDH) which provided a scientific model of disability as well as clarification of the earlier terminology (i.e. impairment, disability and handicap) for clinical use, data collection and research (WHO, 1998). However, in using the ICIDH it became evident that diagnosis alone failed to predict service needs, the level of care provided and required, the outcomes of intervention and/or the receipt of services such as disability benefits, scholastic or vocational performance and social inclusion. These factors together with international focus on the participation and functioning of individuals within a particular community and a sharper look at the barriers that restrict or facilitate participation, necessitated the redefinement of the ICIDH. This process started in 1995 and it is estimated that the complete ICIDH-2 will be available towards the end of 2001 (WHO, 1998).

A major advantage of the ICIDH-2 is that it is a tool which codes information about an individual's health status while at the same time bridging the medical and social approaches to health. It is based on human functioning, and disability is viewed from the perspective of an individual's life circumstances without attempting to "*label people*". The ICIDH-2 is also etiologically neutral, emphasises parity, is culturally appropriate and covers the whole lifespan. It can thus be used by any individual, not only the disabled, making it a universal (and not a minority) model (WHO, 1999). The ICIDH-2 is graphically presented in Figure 2.2.



**Figure 2.2** Graphic presentation of the ICDH-2 (WHO, 1999).

From Figure 2.2. it is seen that the ICDH-2 looks at functioning and disability at three levels:

- **Body level/ Body functions and structure.** This refers to the physiological and psychological functioning of body systems and the body structure, i.e. the anatomic parts such as organs, limbs and their components. This is similar to the impairment level used in the ICDH (WHO, 1980).
- **Individual level/ Activities.** This refers to the range of activities or tasks performed by an individual and is similar to the disability level used in the ICDH (WHO, 1980).
- **Society level/Participation.** This refers to opportunities and/or barriers that impact on the areas of life in which the individual is involved, or has access to and is similar to the handicap level used in the ICDH (WHO, 1980).

In addition, the ICIDH-2 highlights the complex relationship and dynamic interaction between different environmental and personal factors that impact on activity and participation that is associated with health conditions, namely

- **Environmental factors.** This refers to the physical, social and attitudinal environments in which people live and conduct their lives (WHO, 1998). These factors have an external influence on functioning and can impact on all three levels. They are extrinsic (outside of the individual) e.g., the attitudes of society, architectural characteristics or the legal system. Environmental factors are organised from the immediate environment to the general environment. This is similar to the Lloyd, Quist and Windsor (1990) model for AAC, which highlights the importance of different communication environments and partners in service delivery to CSD.
- **Personal factors.** This refers to the features of the individual that are not part of health conditions or functional state. These factors have an internal influence on functioning and may include gender, age, fitness, lifestyle, habits, coping styles, social background, education, past and current experience, overall behaviour pattern, individual psychological assets and other characteristics. These factors impact on resilience and protective factors as discussed in section 2.3.1.3.

Functioning and disability have a complex relationship between the health condition and the contextual factors (e.g. environmental or personal factors). The WHO (1999) uses *functioning* as the umbrella term to indicate positive aspects at all three levels of the ICIDH-2 whilst *disability* is the umbrella term for the negative aspects (problems) at all three levels. Disability is thus seen as a multidimensional phenomenon resulting from the impaired interaction between people and the environment. The focus should not be on the **disability** but on the **ability** and how that can be used optimally to ensure full participation in everyday activities. Brandt and Magyary (1989) refer to this process as one of avoiding difficulties and maximising strengths.

The implications of using the ICIDH-2 for communication training are:

- Greater emphasis on the strengths of CSDs by focusing on their participation in their respective communities with some facing more barriers that restrict participation than others.
- Communication training in its broadest sense, and in particular communication training to CSDs by means of AAC, aims at assisting individuals to become communicatively competent in order to heighten their participation in society (Beukelman & Mirenda, 1998). The ICIDH-2 thus brings disability classifications more in line with the expected outcomes of communication training.
- The stronger focus on social inclusion (participation) highlights the importance of training various communication partners, which might impact on changing of attitudes towards disability (Johnson, Baumgart, Helmstetter & Curry, 1996).
- Provides an indication of the environmental (e.g. lack of communication partners) and personal factors (e.g. limited communication means) that might hamper participation. This information can be used to assist with the planning of communication training.

### **2.3.1.3 Protection**

Protection of children in South Africa takes on many forms. It includes housing (recently the number of homeless children had risen dramatically), the provision of an infrastructure viz. sanitation, water and electricity (25% of schools do not have water within walking distance and 57% of schools do not have electricity) and protection from child labour (hundreds of thousands of South African children between 10 and 14 years of age are engaged in some kind of labour) (NPA, 1999). In addition, children need protection against communicable diseases e.g. TB, cholera and other diseases that threaten their general health e.g. HIV/AIDS. South Africa is facing one of the worst TB epidemics in the world, with over 90 000 new reported TB cases and an estimated 3 000

deaths in 1995 (Government Gazette 17910, 1997). Consequently the Department of Health has declared TB a top national health priority (Government Gazette 17910, 1997). Foetal Alcohol Syndrome is the most common preventable cause of intellectual impairment worldwide, and one which all unborn children should be protected against (Viljoen, 1999). In a study conducted in the Western Cape, 55% of the women in the sample admitted to varying degrees of alcohol ingestion during their current pregnancy, of which the drinking patterns and intake of 23,7% was sufficient to place their unborn children at high risk for Foetal Alcohol Syndrome (FAS)(Croxford & Viljoen, 1999). Children also need protection from abuse and neglect. Children need good nutrition as the nutritional status of children is a sound indicator of overall development and well-being (Government Gazette 17910, 1997). All of these factors affect CSDs to an even greater extent due to their vulnerability and low immunity.

Despite this bleak picture, children have an inherent resiliency. “*Resilience*” and protective factors refer to good developmental outcomes of children from high risk backgrounds who overcome great odds e.g. economic hardships, parental mental illness, child abuse and neglect, teenage motherhood, and peri-natal complications (Werner, 2000). These protective factors exist in multiple domains and can be found within the child, within the family and/or within the community (Beckwith & Sigman, 1995). The factors within the child will be mentioned but not described in detail, as it is not the emphasis of a communication training programme which is focused at a secondary prevention level. These factors include aspects such as low distress, active, alert children with high vigour and drive, sociable children with easy engaging temperaments, children with advanced self-help skills, those who have average to above-average intelligence, an internal locus of control, a positive self-concept and strong achievement motivation (Werner, 2000). Within families some of the protecting factors are small family size (< four children), mother’s level of education, maternal competence, close bond with the primary caregiver and supportive grandparents and siblings (Kaplan-Sanoff *et al.*, 1991; Werner, 2000). Finally, the protective factors in the community need to be addressed. This includes aspects such as having friends, access to schools and having teachers who can become mentors (Werner, 2000).

Although these protective factors are not the main focus of communication training, they should be mentioned within a comprehensive PHC programme, aimed at addressing the communication needs of CSDs. It is expected that an awareness of broader issues will impact on the quality of services provided and therefore the following 2 generic principles and their application to a communication training programme for CSD and their primary caregivers, should be kept in mind:

- A comprehensive PHC approach should address broader issues, such as protective factors. An awareness of protective factors by community health nurses (together with training in collaboration and multiskilling) should enable them to address these issues with the primary caregivers of CSDs. This might in turn impact positively on the grandparents, siblings etc. (Eggbeer, 1995).
- A comprehensive PHC approach should aim at maximising protective factors that have been known to impact positively on development and growth (Meisels, 1992). The maximising of protective factors by community health nurses should impact on the social inclusion of CSDs and impact positively on the number and variety of communication partners that CSDs are exposed to (Johnson *et al.*, 1996).

### **2.3.2 Comprehensive versus selective PHC approaches**

Following the debate related to measuring the effectiveness of PHC programmes, two schools of thought emerged. “*Selective PHC*” focused on the transferring of existing technology and skills in as short a time as possible. This refers mainly to medical interventions aimed at improving the health of most individuals at the lowest possible cost. On the other hand, “*comprehensive PHC*” focuses on the developmental process through which people could improve both their life and their life style, stressing the importance of good health (Rifkin & Walt, 1986).

Selective PHC raises a number of concerns. One of the major concerns being the fact that it negates community participation, reinforcing authoritarian attitudes as professionals decide which aspects should be addressed in the programmes (Brown, Baine & Neufeldt, 1996). This is inconsistent with one of the main focuses of PHC, namely the inclusion of the community in all aspects of service delivery, including a needs assessment. In the past, the exclusion of community members resulted in a lack of representation in community affairs with a consequent neglect of their needs and a skewed view of the realities and needs of the particular community (Brown *et al.*, 1996; Lundgren-Lindquist & Nordholm, 1993). Selective PHC also focuses on individual with so-called “priority diseases”, leaving the rest of the community to suffer. Despite these concerns, this type of model is often selected, due to the fact that funders tend to allocate money for selective PHC projects, as results are recordable (as opposed to measuring abstract variables such as community participation) and the fact that selective PHC service delivery can be provided to a large population (e.g. vaccinations) with relative ease, leading to arguments that it is cost effective (Rifkin & Walt, 1986).

In addition, by identifying and promoting specific programmes, attention is diverted from the process of development (which is the focus of comprehensive PHC). This can lead to selective PHC programmes being seen as “magic bullets” that are fired into countries to solve specific problems, raising false hopes in the communities regarding improved health. Health is thus seen as a static, measurable unit which can be described in terms of health status as a result of the medical intervention (Rifkin & Walt, 1986). The philosophy of the medical model of intervention, namely active service provision by professionals who each focussed on their own discipline, acting as experts who assessed, developed and prescribed services to passive recipients in the communities, thus prevails to a large extent in selective PHC (Atkins-Burnett, 2000).

On the other hand, comprehensive PHC views health as a dynamic changing condition, which is the result of motivation, action and/or attitudes. In an attempt to improve health as such, programmes therefore have to be aimed at improving a wide range of lifestyle issues (Lequerica, 1997). Health is also seen as a condition which improves gradually and instead

of expecting major changes in the shortest time possible, programmes should move one step at a time (Brown *et al.*, 1996). With comprehensive PHC the improvement of health can only come over time as change has to not only be on the health level, but also on the social, economic and political levels (Rifkin & Walt, 1986). The control of the outcome therefore lies in the hands of those who use, or should use the intervention programmes, but due to the different levels of expected outcomes (e.g. social, economic and political), the programme planners have no control.

In the present study, a comprehensive PHC approach is advocated as community health nurses will be trained to provide communication training to CSDs and their primary caregivers. The scope of the training programme should not only focus on one specific skill, but should aim to address prevention, participation and protection of CSDs within a PHC context. In addition, the process of developing such a training programme should be highlighted, as community health nurses should be included in all the phases of development, including the needs assessment. This is an essential element in the empowerment of community health nurses to provide services to CSDs and their primary caregivers which will impact on the sustainability of service delivery. It has been recorded that a personal interest and/or investment in a project, the opportunity to take action and make meaningful contributions and the development and recognition of individual resources, all impact positively on empowerment (Homan, 1999). A training programme should therefore be aimed at adherence to these principles.

## **2.4 TRANSDISCIPLINARY TRAINING : A COMMUNICATION ORIENTATION**

In this section the features of transdisciplinary training and how it relates to communication training, will be described, followed by an outline of the participants involved in the proposed training. This section will be concluded with a description of two approaches to transdisciplinary training in communication training, namely multiskilling and collaboration.

### 2.4.1 Features of indirect services

The provision of beginning communication skills to CSD by means of community health nurses training primary caregivers of CSD, is characterised by an indirect service approach implying that professionals involve themselves as collaborators to a greater extent (Buysse, Schulte, Pierce & Terry, 1994). This should, however, not imply that professionals provide less direct, hands-on services. In fact, professionals who cease to do this, become less effective professionals, both to clients and colleagues. According to Orelove and Sobsey (1996) indirect service delivery to CSDs incorporates four basic assumptions, which are described in Table 2.2. The realisation of these assumptions for communication training is also included.

**Table 2.2 Indirect service delivery: basic assumptions and realisation for communication training**

Indirect therapy assumptions	Realisation of assumptions for communication training
Milieu teaching yields best results with CSDs	Communication training should be conducted in the natural environment by the primary caregiver (Leahy,1989). All communication means and functions are thus embedded naturally during the CSDs routine and are not seen as separate aspects that require training (Bricker, 1992). Therefore additional “ <i>communication time</i> ” or “ <i>therapy time</i> ” is not set aside (McGregor, Young, Gerak, Thomas & Vogelsberg, 1992).
Activities should be functional	ADL (e.g. mealtime, washing and dressing) can provide the content for interaction training (Coupe, Barton & Walker, 1992). These activities should be conducted in a functional manner, i.e. at appropriate times during the day with natural consequences, e.g. if CSDs request “ <i>more porridge</i> ” during mealtime, more porridge is given (McGregor <i>et al.</i> , 1992).
Rehabilitation should be provided throughout the day and in all the settings in which CSDs function	Research has shown that “ <i>salt and pepper contacts</i> ” spread throughout the day yield favourable results with CSDs (McCormick & Schiefelbusch, 1984). Therefore activities that occur relatively frequently should be selected. The nature of many of the communication functions that are taught should be generic, e.g. requesting “ <i>more</i> ” which can be used irrespective of the activity. Likewise, the deliberate creation of communication opportunities should not be restricted to specific activities, e.g. putting a desirable object out of reach.
Skills must be taught and verified in settings in which they occur naturally.	Primary caregivers should be taught how to provide communication opportunities within naturally occurring settings throughout the day in order to enhance and extend communication functions and means, and how to be sensitive towards existing communication attempts (Reichle, Miranda, Locke, Piché & Johnson, 1992).

The second major feature of transdisciplinary training is that it is characterised by role transition. This implies the crossing of traditional disciplinary boundaries where professionals work together and share their expertise and exchange certain roles and responsibilities to develop new ideas and strategies for service provision (Chapman & Ware, 1999; Lloyd, Fuller & Arvidson, 1997; Orelove and Sobsey, 1996). This would specifically mean that the skills associated with one profession could be taught to others who work with the specific client, e.g. the SLP can train community health nurses to train primary caregivers how to deliberately provide communication opportunities to CSDs when teaching the concept of “*requesting help*”. This will lead to less fragmented services and will provide CSDs with more opportunities to practise this communication function. Role transition is a process and consists of six separate but related processes, (Orelove & Sobsey, 1996; Parker, 1994) which are described in Table 2.3. The realisation of these assumptions in communication training is also included.

**Table 2.3 Role transition process and realisation in communication training**

<b>Role transition process</b>	<b>Realisation in communication training</b>
<b>Role extension</b> Increasing theoretical knowledge and clinical skill in own discipline.	Emphasise the nursing task (e.g. prevention). This is similar to multiskilling Level 1.
<b>Role enrichment</b> Development of a general awareness and understanding of the terminology and basic practices of other disciplines.	Programme should explain concepts such as “ <i>communication</i> ” and “ <i>severe disability</i> ” which are novel to community health nurses. Service delivery to CSDs traditionally takes on the form of direct referral. Training aimed at increasing the knowledge in the communication and disability fields by explaining some of the basic concepts. This is similar to multiskilling Level 2.
<b>Role expansion</b> Acquiring sufficient information to make knowledgeable observations and recommendations outside own discipline.	Sensitising of community health nurses to the issues pertaining to CSDs and their primary caregivers and enabling them to make informed recommendations while also providing support. This is similar to multiskilling Level 3.
<b>Role exchange</b> Learning the theory, methods and procedures of other disciplines and beginning to implement the techniques.	Equipping community health nurses with the necessary knowledge and skills to provide basic services to CSD and their primary caregivers. Four important communication elements, namely communication functions, means, partners and how to create deliberate communication opportunities should be addressed (Reichle, <i>et al.</i> , 1992). This is similar to multiskilling Level 4.
<b>Role release</b> Putting newly acquired techniques into practice with consultation from the team member from the discipline is accountable for those practices.	After initial training, all community health nurses should be visited in situ to assist them with the implementation of the communication training programme and to help with problem-solving of difficult cases. The effective functioning of a professional at this level is often dependent on whether this type of support is given. In training efficient transdisciplinary professionals caution should be taken not to terminate training without this process.
<b>Role support</b> Informal encouragement from other team members and back-up support by the team member for the appropriate discipline.	A cadre of community health nurses from the same health district (Moretele) should be trained to provide an infrastructure for service delivery to CSDs in this area. In addition, the trainer should be available to the community health nurses for an extended time.

From this discussion it is clear that in order to function effectively as a transdisciplinary professional, knowledge and skills are crucial features. One way of equipping professionals with the necessary knowledge and skills is through the use of multiskilling. This will be described in detail in Section 2.4.3. This leads to the question of who the participants in the proposed transdisciplinary training are.

## 2.4.2 Participants

As discussed in the previous section, transdisciplinary training has two major features, namely indirect service delivery and collaboration, raising the question as to who should participate in this process. In a communication training programme aimed at a PHC

level,, three major participants are involved, namely the community health nurses, the primary caregivers of CSDs and the CSDs themselves. Brief mention will also be made of “other” participants, who are involved to a lesser extent namely the community at large and other professionals. However, it should be noted that although the roles of all these participants are mentioned, the focus of this research is on the community health nurse.

#### **2.4.2.1 Community health nurses**

Community health nursing is not merely the performance of nursing activities in the community setting. It should rather be seen as ongoing, comprehensive and general practice that is not limited to a specific age or diagnostic group aimed at the promotion of health and the prevention of illness (Clark, 1996; Lerner & Ross, 1991). It is also differentiated from other nursing fields by the fact that it includes nursing directed at individuals, families and the community at large, placing community health nurses in a prime position to assist with the paradigm shift away from the medical model to the social model of service delivery (Thomas, 1999a).

Defining the roles of community health nurses is difficult due to the fact that it remains in transition due to the changing needs of the communities they serve (Clark, 1996). However, regardless of the setting in which community health nurses work, they must be capable of performing certain generic roles. These roles within the four multiskilling levels (as discussed in Section 2.4.3) are depicted in Figure 2.3.

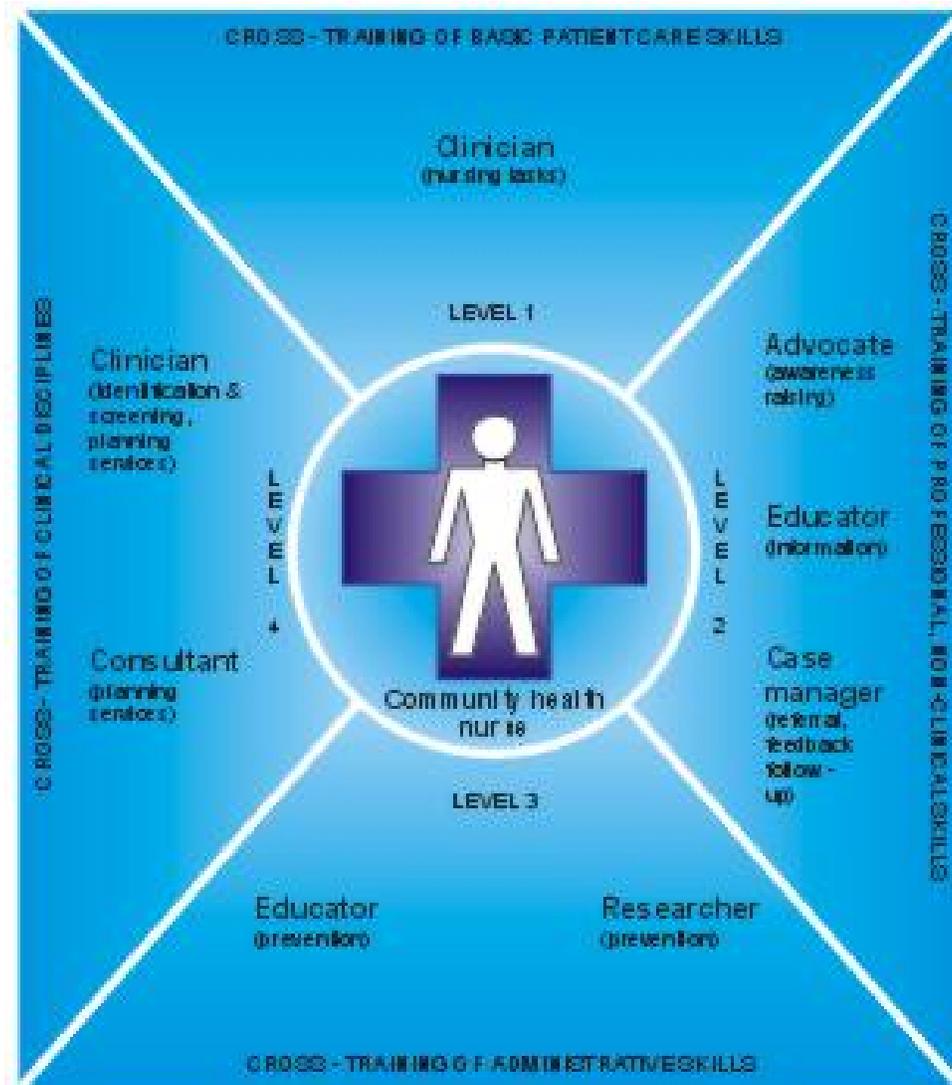


Figure 2:3: Roles and tasks of community health nurses within multi-skilling levels

Regarding the first multiskilling level, the community health nurse has the role of *clinician*. Community health nursing includes both personal health (that focuses on the individual and mostly includes the maintenance of health and recovering from illness) and public health (that promotes and protects health of the community) (Wilkey & Gardner, 1999; Thomas, 1999a). At this level the activities mostly refer to traditional nursing tasks based on the basic nursing curriculum. Therefore it will not be discussed any further.

At the second multiskilling level the community health nurse has three major nursing roles, that of advocate, educator and case manager. The *advocate* role requires of the community health nurse to speak or act for individuals who may be unable to speak for themselves (e.g. CSDs and their primary caregivers) (Clark, 1996; Glassman-Feibusch, 1984). The reasons for this may include a lack of knowledge, difficulty or inability to articulate needs or ideas, fear, perceived lack of power and/or intellectual/physical disability (Wilkey & Gardner, 1999). However, advocacy does not only mean taking the part of others, it also entails the preparation of individuals to stand alone and speak for themselves rather than remaining dependent of the nurse (e.g. by introducing them to DPOs) (Clark, 1996). Because of the close contact with CSDs and their primary caregivers nurses are often the best health professional to promote their needs and desires. One of the major nursing tasks would be awareness raising in the community about disability issues, e.g. by having health talks. Linked closely to the advocacy role is that of *educator*. Health teaching and the provision of information are viewed as essential nursing responsibilities. This can be conducted at the individual level (assisting CSDs and primary caregivers to make informed decisions about rehabilitation) or at a community level (e.g. health talks about disability) (Wilkey & Gardner, 1999). Thirdly, the nurses act as *case managers* at this level, implying the application of strategies for co-ordinating and allocating services for individuals who cannot manage their own care (e.g. CSDs and their disempowered primary caregivers) (Lerner & Ross, 1991; Wilkey & Gardner, 1999). The primary nursing tasks as applied to CSD and their caregivers would entail identification of CSDs, referral when needed, highlighting the importance of feedback and follow-up in an attempt to monitor progress. Community health nurses should be sensitive to the needs and circumstances of the primary caregivers as they may appear to be non-compliant (e.g. may not attend referral and/or not return for feedback and follow-up) if they do not share the professional's values and priorities which in turn leads the nurse to experience frustration and hostility (Humphry, 1995).

At the third multiskilling level community health nurses act primarily as *educators* and researchers. The importance of education has already been highlighted. At this level

education is specifically related to the prevention of disability (at primary, secondary and tertiary levels). In order to enhance this prevention function, the community health nurse also has to act as *researcher* (Wilkey & Gardner, 1999). This may include tasks such as identifying problem areas, collecting, analysing and interpreting data, applying findings, and evaluating, designing and conducting research (Griffith, 1994; Wilkey & Gardner, 1999). Research is an excellent tool in addressing the complex issues pertaining to prevention.

Finally, at the fourth multiskilling level, the nurse also has two main functions – that of clinician and that of collaborator. The role of *clinician* at this level is broader than on the first level as it also entails a rehabilitation function. At this level it is expected that nurses act as transdisciplinary professionals, moving beyond the traditional boundaries of their discipline. It requires that community health nurses identify, screen and plan services for CSDs. Grebin (1981) spelt out what the exact nursing tasks with specific populations, e.g. a child with Down Syndrome, would be. This included determining aetiology (to provide genetic counselling), assessment and the management which entails counselling / prevention, follow-up, providing medication, collaboration and referral. The *collaborator role* is closely linked to providing services. This is also closely linked to other roles (e.g. advocate and educator) as consultancy requires of community health nurses to help individuals to understand their disability and to make knowledgeable decisions about their own rehabilitation.

One of the specific settings in which community health nurses are required to function, are rural PHC clinics. These clinics are usually single settings which are visited by individual clients with a wide range of health problems (Lequerica, 1997). According to the Department of Health (1999) these clinics should render comprehensive integrated PHC services using a one-stop approach (also termed “*supermarket approach*”) for at least 8 hours a day, 5 days a week. In addition, a seamless system of care is also promulgated. A seamless system of care is one which provides primary, secondary and tertiary services to ensure continuity. Although care at all three these levels is not offered at rural PHC clinics, community health nurses working at this level must be able to

arrange for services at the other levels (Roberts, Rule & Innocenti, 1998). In addition, a seamless system of care provides the full array of services through collaboration with various partners (e.g. in the public or private sectors) that allow access to all families needing a service, regardless of their ability to pay (Roberts *et al.*, 1998). In South Africa access to health services is ensured for all children under six years of age, but this is restricted as it refers only to public services. Collaboration with the private sector is seldom seen and then usually only if payment for the services can be guaranteed. Finally a seamless system of care helps families through the transition from one clinic to another (e.g. should they move) so that there is not a breakdown in services (Roberts *et al.*, 1998). In conclusion, it can thus be said that a seamless system of care is ideal, as it would create a safety net for all individuals within a particular community. In reality, however, this has not as yet been implemented effectively in the South African context.

The specific requirements of rural PHC clinics necessitate community health nurses to function in a slightly different manner. Community health nurses at these clinics:

- must be expert generalists because of the diverse skills they need when working with individuals across the lifespan with diverse health conditions (Clark, 1996; Hamell-Bissell, 1992; Tiffany & Hourigan, 1992).
- need to be independent and self-reliant since they make on-site decisions at clinics that can be some distance from support (Thobaben & Biteman, 1999).
- should have community ties and relationships, which provide close family contact and potential for continuity of care. Must be able to tap local resources (Eayrs & Jones, 1992; Hamel-Bissell, 1992; Thobaben & Biteman, 1999).
- have a high social visibility (leading to relatively little privacy) and their social and professional roles intertwine to such an extent that inadvertent breaches of confidentiality are a concern (Hamell-Bissell, 1992).
- have a positive community visibility that has been linked to professional pride, self-esteem, and potential role in shaping health policy at the community level (Tiffany & Hourigan, 1992).

- require a broader blend of knowledge and skills because fewer service options are available (Hamel-Bissell, 1992; Thobaben & Biteman, 1999).
- display certain personal attributes including a higher level of emotional maturity and a greater desire for autonomy (Hamel-Bissell, 1992).

The major problems experienced at these rural PHC clinics relate to professional isolation, limited support services, insufficient continuing education opportunities, limited peer contact, excessive workloads and time demands (Gordon, 1994; Tiffany & Hourigan, 1992). In order to address these problems, to meet the diverse demands placed on community health nurses, and to be compatible with the new health care environment which requires more flexibility in the deployment and management of health resources, interesting trends in service delivery are seen (Salvatori, 1997). Two suggested approaches in a communication training programme to address these issues are multiskilling and collaborative practice which are described in detail in Sections 2.4.3 and 2.4.4 respectively.

#### **2.4.2.2 Primary caregivers**

Primary caregivers are defined as those individuals who assume the majority of caregiving responsibilities (Shippee-Rice & Mahoney, 1992). In southern Africa these are primarily mothers, as many women are abandoned by their husbands as a result of the birth of their disabled child (Miles, 1996).

The belief that service delivery to CSDs is a complex and specialised task that should be left to professionals, is visible in the fact that primary caregivers are not getting enough help with the care, education and training of their CSDs (O'Toole, 1988). This was highlighted in a study by Dunbar & Reed (1999) where professionals who work at PHC clinics reported a lack of awareness of primary caregivers regarding developmental milestones and how to foster developmental skills, as well as a need for support in child

rearing. It was also noted that limited opportunities for typical play experiences exist and that primary caregivers are unaware of disciplinary alternatives (e.g. available services).

The lack of support to, and training of primary caregivers happens despite the fact that the importance of training is highlighted time and again in the literature (Coats & Lewis, 1984; House *et al.*, 1990; Kalmanson & Seligman, 1992; Kelly & Barnard, 2000; Ramey & Ramey, 1992). Early, intensive family support has the potential to improve long-term functioning in families, stressing the fact that social support to the primary caregiver as a protective factor, should not be overlooked (Beckwith & Sigman, 1995). If training is therefore focused on achieving long-term effects it should focus on increasing the primary caregiver's knowledge, attitudes and practices regarding the child's development (Downs & Walker, 1996; Parush & Hahn-Markowitz, 1997). Primary caregivers should share the responsibility of rehabilitation and care with professionals to ultimately lead to joint decision-making (Chapman & Ware, 1999; McDaniel, Campbell & Seaburn, 1990). Primary caregivers should also act as a support network for each other and opportunities for them to meet and share ideas and experiences and to help solve each other's problems should be a high priority of any programme (Atkins-Burnett & Allen-Meares, 2000; House *et al.*, 1990). The fact that they often share beliefs, behaviours and values with other parents in a similar position, makes them ideally suited to take on this role (McDaniel *et al.*, 1990). PHC settings are the most logical and likely place to start when capturing interest and involvement of parents who feel motivated and willing to help (Downs & Walker, 1996; Dunbar & Reed, 1999). Case-Smith (1997) also reported that sustainability is increased if the proposed service could be latched onto an existing service (e.g. latching communication training to clinic visits).

It has been reported that primary caregivers have a positive effect on their children's development and that guidance enhances their ability to function comfortably and completely in their parental role (Case-Smith, 1997). Links have been found between parent-child interaction and the child's later cognitive and social development (Mavrogenes, Bezruczko & Hagemann, 1996; Ramey, Farran & Campbell, 1978; Sameroff, Seifer, Barocas, Zax & Greenspan, 1987). It has also been reported that if

primary caregivers participate in training programmes which emphasise empowerment and nurturance, a number of positive outcomes that will impact favourably on the growth and development of their CSDs are seen (Case-Smith, 1997; Downs & Walker, 1996; Blumberg, 1987), including:

- Increased sensitivity and responsiveness towards their children, resulting in more positive parent-child interaction.
- Heightened involvement with their children, resulting in improved physical care.
- Increased enjoyment of the child resulting in increased stimulation and interaction.

These training programmes also tend to increase parental nurturance and mothering (Provence, 1985). Mothering can be described as intrinsically (actions and responses that are naturally mediated) and learned (where knowledge is gained about child development). This knowledge is gained in a variety of ways, including the modelling of one's own mother's behaviour, through the dynamic involvement with the child, through reading literature on child development and also through attending mothers' groups (Provence, 1985). In a study conducted by Parush & Hahn-Markowitz (1997) it was found that prevention programmes contributed to the mother's knowledge about child development, regardless of the number of years of formal education, thus minimising the effect of formal education. This aspect is particularly relevant in the South African context where a large proportion of mothers do not have more than 13 years of formal schooling and research has shown that with higher education comes a greater awareness and knowledge of child development. However, it was reported that the determining fact in increasing knowledge and skills in the specific study was the mother's drive to learn new skills and the awareness that she needs new skills (Parush & Hahn-Markowitz, 1997). In cases where a mother is unaware or unmotivated that she needs mothering skills, motivation and encouragement from an outside source is needed. From the above it is clear that the involvement of primary caregivers is essential for young children, as they provide the guided stimulation and take on the roles of observer, describer, interpreter,

evaluator and validator of behaviour inside and outside service delivery (Blacklin & Crais, 1997).

In conclusion it can be said that long-term benefits of early intervention programmes appear to be closely linked to the inclusion of primary caregivers as active participants in efforts to bring about change and facilitate development (Chapman & Ware, 1999; Kelly & Barnard, 2000; Provence, 1985). It should also be stressed that parent-professional collaboration is a continuous process (Brandt & Magyary, 1989). Furthermore, research showed that the nature of interaction is more important than teaching the child specific skills or directing his activities (Case-Smith, 1997). The reason is that the primary caregiver's interactional style highly influences the child's development. Two important aspects of the primary caregiver's interactional style have been singled out as important predictors for outcomes: their control (directiveness) and their responsiveness (based on sensitivity). Regarding children's behaviour, three important aspects have been singled out: attention, readiness and responsiveness (Kelly & Barnard, 2000). It should, however, be noted that if a child has a disability, not only the quantity but also the quality of interaction is changed.

Several factors contribute to feelings of satisfaction in caring for CSDs or mediating the level of burden and stress, e.g. the empowerment of knowing what to do (Shippee-Rice & Mahoney, 1992). Higher levels of satisfaction reduce the chances of abandonment and institutionalisation. Consequently programmes must be sensitive in promoting and reinforcing factors that enhance the caregiver's experiences but should also look at caregiver's stress and burden (Dunst, Trivette & Deal, 1994; Shippee-Rice & Mahoney, 1992). This includes the extent of disruptions or changes in the caregiver's life and household as well as the stress and nervousness related to the situation and the extent to which the caregiver feels manipulated by the CSD. Caregiver stress leads to "burn out", the development of health problems and the provision of poor care and possibly mistreatment the CSD (Shippee-Rice & Mahoney, 1992).

One way of counteracting caregiver stress is by joining a support group and being involved in disability and advocacy groups (e.g. DiCAG). In South Africa primary caregivers have argued that they are disabled by virtue of being full-time carers of their CSDs and that together with their children they are affected by the stigma of disability (Miles, 1996). Consequently they joined DPOs which enabled them to pursue their own specific agendas while at the same time maximising the opportunity of being part of the disability organisation (Miles, 1996). These primary caregivers no longer feel isolated and “left out”. The key to sustainable service provision is empowerment of primary caregivers as they are learning new skills, acquiring a raised self-esteem and confidence and are committed (Dunst *et al.*, 1994; Miles, 1996). Trained caregivers experience changes in attitude and have a greater appreciation for disability issues. They often feel committed towards rehabilitation, the changing of negative community attitudes, the counselling of other CSDs and their caregivers about education, employment and rehabilitation. They consider themselves as a responsible resource in their communities which has given them the confidence to provide advice and information to families, support groups and self-help groups (Miles, 1996). The community health nurse can play a definite role in assisting primary caregivers to join support groups and DPOs.

This discussion has argued that involvement of the primary caregivers is non-negotiable when attempting to ensure sustainable service delivery. The importance of involvement, empowerment (to facilitate joint decision-making) and the joining of DPOs as a method of decreasing caregiving stress and increasing competency, were emphasised. A communication programme should thus aim at the training of the primary caregiver (as well as any other interested person, (e.g. older sister), by a trusted person from the community, to facilitate basic communication principles in the particular child. In order to ensure sustainability of services the training programme should have a transdisciplinary PHC focus, while being accessible, available, acceptable, equitable and be conducted in a spirit of collaboration in order to ensure prevention, protection and participation for the CSD. The community health nurse is in an excellent position to conduct this type of service given the fact that she receives knowledge and skills training.

### 2.4.2.3 Children with severe disabilities

Research has indicated that the majority of children with mild to moderate intellectual impairment come from families with extremely low resources and with parents who have limited intellectual resources themselves, but these families are the ones most in need of early intervention and who benefit the most (Ramey & Ramey, 1992). Young children of low IQ mothers (mothers with an IQ<70) are particularly vulnerable if they are not exposed to early, intensive intervention. Fortunately research indicated that these children respond positively to intensive, high quality intervention, leading to a dramatical decrease in the rates of intellectual impairment (Ramey & Ramey, 1992.) Young children thrive in a supportive environment that offers basic opportunities and interaction with those who are responsible for their everyday well-being (Ramey & Ramey, 1992).

Within the sphere of CSD one particularly vulnerable group are the beginning communicators. According to Beukelman & Mirenda (1998) beginning communicators refers to individuals across the age range who have one of more of the following characteristics:

- They do not demonstrate communicative intentionality
- They rely primarily on pre-linguistic communication means such as gestures, vocalisations, eye-gaze and body language
- They are learning to use aided or unaided symbols to represent basic messages for communicative functions such as requesting, rejecting, sharing information and engaging into conversations
- They use low technology communication means (e.g. communication boards, switches or electronic devices with limited message abilities) for communication and participation.

Beginning communicators should be the target population for intervention for a number of reasons. Firstly, due to the fact that CSDs who do not receive services from a relatively

early age (as typically seen in rural areas in South Africa) often remain at this level of interaction. Secondly, the term “*beginning communicators*” includes individuals from across the age range which typically covers the different age groups that community health nurses would be confronted with in PHC clinics. Although it could thus theoretically include adults, the focus of this research is on children. Thirdly, it encompasses individuals with a wide variety of disability types, and is not specific to only one aetiology – as such a specific programme runs the risk of being so “elitist” that it is never used. There is evidence that individuals who experience similar communication difficulties (e.g. beginning communicators) have much in common regardless of the specific disability involved (Granlund & Sundin, cited in Granlund & Olsson, 1999). Finally this may also include individuals who have a mild or moderate disability and who are in the early stages of rehabilitation. All beginning communicators require support to learn that through communication they can have a positive impact on their environment and the people around them – the beginning of participation.

It is also important to note that if beginning communicators is the target population, early intervention would be ensured. Early intervention in this sense is a broad term which refers to a timely intervention, and as often stated in the literature the earlier intervention starts, the better (Meisels, 1992). Due to the fact that beginning communicators are not necessarily ascribed to a specific age group, early intervention in this sense should not be confused with early childhood intervention that typically refers to children aged 0 – 3 years (Louw & Weber, 1997) or the expanded version of this definition used by the Department of Health which includes all pre-schoolers (typically 0 – 6 years)(Government Gazette, 17910, 1997).

Bronfenbrenner (1994) identified three important types of characteristics of this population which are likely to impact on the outcome of the service delivery, viz.

- ***Personal attributes.*** This includes the type of disability, age and gender. These aspects have a weak to moderate influence on the effects of communication intervention in everyday interaction.

- ***Personal qualities.*** This relates to all the factors that invite or discourage reactions from the environment and includes the bio-behavioural state (alertness level), the individuals affective expressions and the temperament/behaviour style (fussiness, frustration and goal-directedness). These three aspects have an impact on the frequency and type of communication interactions.
- ***Developmentally structuring attributes.*** These attributes include aspects such as intellectual curiosity and exploration of the environment and involves the active orientation towards the environment.

It can be seen that these characteristics are closely related to the protective factors mentioned in section 2.3.1.3.

#### **2.4.2.4 Others**

“*Others*” refer to participants who are not necessarily directly involved in communication training, but who should be considered throughout the training process to ensure the sustainability of the services. It includes the community at large and other professionals.

##### **i.) Community at large**

In placing service delivery within a PHC approach, it must be acknowledged that rehabilitation is too important to be left only to the professionals (Thorburn & Marfo, 1990). Communities have to be made aware of the 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). The “*person-within-community*” principle, should be adhered to at all times as all individuals are part of a larger community (Kelly & Barnard, 2000; Murray, 1980). Community participation is the heart of PHC and should capitalise on the community members’ experiences, wisdom and cultural sensitivity (Rifkin, 1986). Furthermore, service providers and communities often do not discuss their expectations of PHC, leading to expectations not being met, resulting in decreased motivation and

participation. It is important to realise that community participation is a dynamic process that constantly changes and it should remain flexible as people and objectives change. For communication training to thus be effective, community health nurses should be encouraged to have frequent health talks on disability and related issues in order to raise awareness of these issues. They should also be encouraged to assist DPOs in their specific communities by raising awareness of the existence and operation of these DPOs.

## ii.) Professionals

Transdisciplinary training does not attempt to negate the importance of specific disciplines. Rather it attempts to create a greater understanding and appreciation of the specific roles of each of the disciplines involved. It also emphasises the role of closer collaboration between team members (Blackstone, 1995). The traditional roles of therapists are changing despite the initial inertia. In order to increase time management and to provide services to all in need, they need to refocus their attention on consultation and collaboration as opposed to providing direct therapy (Hesketh and Hopcut, 1997). In future professionals (and in particular therapists) will become increasingly important as trainers and they will have to adapt their professional skills and share their knowledge (House *et al.*, 1990).

An effective communication training programme should address the issue of a shortage of trained professionals who could provide rehabilitation services to CSDs (Bortz *et al.*, 1996; Moodley *et al.*, 2000). It should also regard service delivery to this population as too important to be left until such a time as professional involvement seems feasible (Jephson, 1992). Thus the focus should be on training community health nurses to provide a basic level of communication training to CSDs and their primary caregivers in an attempt to initialise the rehabilitation process.

### 2.4.3 Multiskilling as integrally related to transdisciplinary training

Multiskilling is a form of role diversification and refers to the cross-training of professionals to perform procedures and functions in two or more disciplines (Allerton, 1997; Salvatori, 1999). It is thus a redesign strategy aimed at enhancing cost-effectiveness, efficiency, quality and co-ordination of services (ASHA, 1996). Multiskilled health professionals can be defined as *“Persons cross-trained to provide more than one function, often in more than one discipline. These combined functions can be found in a broad spectrum of health related jobs, ranging in complexity from the non-professional to the professional level, including both clinical and management functions. Traditional functions (skills) added to the original health care worker’s job may be of a higher, lower or parallel level”* (Bamberg in ASHA, 1996:54).

Multiskilling is much more than simply transforming staff into *“jacks of all trades”* (Salvatori, 1997). It offers opportunities for job expansion and job enrichment in the shape of new or expanded roles and responsibilities, skill sets and job titles, and it usually implies in-service training rather than formal education (as is done in the BCIP training). It does not mean the loss of one’s professional identity nor does it imply the demise of specialists. Opportunities exist for all service providers to maintain their speciality skills and at the same time develop or expand roles, skills sets without giving up their professional identity (Salvatori, 1997). Service providers with skills and competencies in more than one area are likely to be regarded as more cost-effective and more employable than their traditional single skilled counterparts (ASHA, 1996). Multiskilling was selected as the initiative by which community health nurses are equipped with transdisciplinary skills to deal with the problems that confront them in rural PHC clinics when having to deliver high quality sustainable services to CSDs and their primary caregivers.

As discussed in this chapter an increasing emphasis on community health versus individual health, community-based care versus hospital-based care and health promotion and illness prevention versus curative approaches are currently seen (Salvatori, 1997). The role of community health nurses was elaborated as they are often the first and only professionals in rural areas where no other services are available and therefore they

should take leadership roles in emphasising the need for human care, as the right to health is one of the principles of *Health for All by the Year 2000* (Graham, 1981). This is further enhanced by the fact that they understand the concerns of the people they serve – they see where people work, play, live, study, worship and die (Humphry, 1995). In addition a shortage of manpower to provide services to CSD is experienced. Although community health nurses are thus in an excellent position to provide services to CSDs and their primary caregivers, traditional nursing curriculums do not include specific service delivery strategies for this population. One way in which this can be addressed is through the multiskilling of community health nurses to equip them with the knowledge and skills to function as transdisciplinary professionals. Therefore the focus of a communication training programme should be on training community health nurses to provide a basic level of services to CSDs and their primary caregivers in an attempt to initialise the rehabilitation process.

A communication training programme that focuses on CSDs and their primary caregivers, raises the question as to why community health nurses should know about disability. They include:

- Community nurses are often the first professionals who come into contact with CSDs who are able to participate on different levels, depending on the degree and type of disability (Clark, 1996). In about 90% of cases intellectual impairment is moderate (IQ of 50 – 70) and with proper support and nurturing these children can live and learn in the community. It is known that most of these children live at home with their parents (or extended families) and thus need to adapt to community living, making it mandatory that their needs be viewed within the context of the family and the community (Freeman & Heinrich, 1981).
- The impact of disability is profound. It is permanent, placing high financial and care demands on the family and on the community (Beukelman & Mirenda, 1998). Timely services to this population will impact positively on the financial and care demands. There has also been evidence that if mothers of CSDs receive

training, they are more likely to be employed (Case-Smith, 1997; Downs & Walker, 1996).

- A strong move away from institutionalisation to “*inclusion*” of CSDs in all aspects of community living and learning (with increased participation of CSDs) is noticeable. This implies that CSDs are not sent to boarding facilities at an early age and that they remain in their communities for longer periods (Orelove & Sobsey, 1996). Consequently community health nurses come into contact with CSDs and their primary caregivers over longer periods of time.
- Community health nurses are part of the PHC team and often act as the bridge between caregivers and professionals. Caregivers usually perceive the nurse as an approachable and concerned advisor who can identify with the problems that concern the family. They will therefore discuss problems with her that they feel are too trivial to discuss with the doctor (Shanks, 1983). In addition the nurse also contributes valuable knowledge to the rest of the team due to her particular training, expertise and function (Bailey *et al.*, 1990). As previously mentioned, the importance of transdisciplinary functioning in a team is necessary when implementing community-based, family-centred, comprehensive and co-ordinated health care to disabled children and their families (ASHA, 1989).
- In view of the shortage of qualified health care professionals in South Africa (Bortz *et al.*, 1996), the community health nurse is ideally positioned to provide services to primary caregivers of CSDs (Moodley *et al.*, 2000). She is equipped to perform this task as she is viewed as a sensitised professional who has the skills to observe behavioural patterns and environmental concerns and thus able to make recommendations where necessary.

Consequently the pivotal role of the community health nurse within PHC rural clinics, together with the changing of services towards more client-centred, holistic, wellness-focused and community-based care, necessitates multiskilling. This is further compounded by factors such as changing demographics (with the majority of people in rural areas being very young or very old), technological advances and consumer

expectations which have contributed to the demand for more equitable distribution of resources, improved efficiency, public accountability and more consumer participation in decision-making (ASHA, 1996). Individuals are taking more interest in their own health, and want to choose their own service providers. Quality management demands more client-focused care and more emphasis on effectiveness and efficiency, including improved health outcomes.

In the proposed training programme, multiskilling was addressed by looking at the specific nursing tasks and its application to disability. This is also related to the different roles of the community health nurses as depicted in Figure 2.3. The four-multiskilling levels and how they apply to disability are provided in Table 2.4.

**Table 2.4 : Multiskilling levels as applied to various nursing tasks and disability**

Multiskill level	Nursing task	Application to disability
<b>Level 1</b> Cross-training of basic patient care skills		Not addressed in a communication training programme, as this is part of the regular nursing curriculum.
<b>Level 2</b> Cross-training of professional, non-clinical skills	Awareness	<ul style="list-style-type: none"> <li>▪ Create community awareness regarding the needs of CSDs.</li> <li>▪ Discuss community awareness with other professionals (e.g. school nurses and teachers).</li> <li>▪ Make parents and teachers aware of the importance of adequate, effective and appropriate communication skills.</li> </ul>
	Information	<ul style="list-style-type: none"> <li>▪ Provide information regarding CSD.</li> <li>▪ Provide information regarding expectations.</li> <li>▪ Provide information regarding further communication needs (long-term plan).</li> </ul>
	Referral	<ul style="list-style-type: none"> <li>▪ Initiate referrals to therapists.</li> <li>▪ Initiate referral for further medical management.</li> <li>▪ Assist therapists and teachers in determining whether a medical referral is necessary.</li> </ul>
	Feedback	<ul style="list-style-type: none"> <li>▪ Make primary caregivers aware of the importance of providing feedback to referring nurse.</li> <li>▪ Encourage other professionals to provide feedback to referring nurse.</li> <li>▪ Provide feedback to caregiver regarding the changing communication skills after implementation of the protocol.</li> </ul>
	Follow-up	<ul style="list-style-type: none"> <li>▪ Encourage caregivers to bring their children for regular follow-ups to monitor progress.</li> <li>▪ Assist caregivers to monitor the quality and quantity of communication (use the progress chart).</li> </ul>

Multiskill level	Nursing task	Application to disability
<b>Level 3</b> Cross-training of administrative skills	Prevention	<ul style="list-style-type: none"> <li>▪ Educate the community on causes of disability and how some conditions can be averted and prevented, e.g. pre-natal care, good nutrition (To some extent already being done).</li> <li>▪ Refer high-risk mothers.</li> <li>▪ Educate on compliance with appointments (doctors, hospital, therapists, etc.), medication (e.g. epilepsy), periodic health visits (growth chart) and follow-up.</li> </ul>
<b>Level 4</b> Cross- training of clinical disciplines	Identification and screening	<ul style="list-style-type: none"> <li>▪ Identify children who are at risk of disability (e.g. twins, very low birth weight, poor nutrition, etc.) according to health history.</li> <li>▪ Conduct health assessment on identified children (at-risk and established risk).</li> <li>▪ Obtain baseline data on current functioning</li> <li>▪ Assist in obtaining the necessary medical evaluations.</li> </ul>
	Planning services	<ul style="list-style-type: none"> <li>▪ Initiate and implement the proposed beginning communication intervention protocol.</li> <li>▪ Suggest modifications to present communication means, functions opportunities and partners.</li> <li>▪ Reassuring caregivers of humanity and likeability of CSDs.</li> <li>▪ Encouraging caregivers of CSDs to start a support-group while waiting at the clinics.</li> <li>▪ Sustaining families through support and being an anchor (willing to listen and help).</li> </ul>

Modified and based on ASHA 1996, Dublinske, 1983, Mast 1983, Freeman & Heinrich, 1981 and job descriptions for community health nurses provided by the Assistant Director of Health in the Moretele Health District).

When looking at these multiskilling levels, it is important to note that these skills cannot be viewed as distinct categories and that extensive overlapping occurs. These skills are also dynamic in nature and may therefore change over time. However, in an attempt to clarify specific nursing tasks as it pertains to disability, this distinction was made.

#### 2.4.4 Collaboration as integrally related to transdisciplinary training

The second feature that is central to training transdisciplinary service delivery is collaboration. Collaboration is a process of joint decision-making in an atmosphere of mutual respect and co-operation (Buysse *et al.*, 1994; Wilkey & Gardner, 1999). Collaboration is required at many different levels. Firstly, the concept of holism in service delivery is emphasised as the CSD is viewed in interaction with the primary caregiver (usually the parent), but also as part of the community at large. This makes it

necessary for the community health nurses to collaborate closely with primary caregivers, and also with community members. Secondly, collaboration with other professionals are also required – ranging from other health care professionals (fellow nurses, doctors and therapists) to educational professionals (e.g. teachers) and professionals in the human and social fields (e.g. the church, social workers, psychologists, etc). It is important to note that this perspective should be kept at all times as one type of collaboration cannot be seen without being aware of the others.

Collaboration emanates from an understanding and appreciation of the roles and contributions that each discipline brings to the service delivery experience (American Association of Colleges of Nursing, 1996). While each discipline has its own focus, all participants are equal partners with mutual understanding and respect for the actual and potential contributions of the other disciplines as basis. Professionals, should therefore be seen “*as part of*” the service delivery plan and not as “*apart from*” this plan (McDaniel, *et al.*, 1990).

As mentioned earlier, the ability to collaborate is clearly vital when the plethora of health professionals and their increasing specialisation and role differentiation combine with the complexity of demands made by CSDs. Sharing information and the planning of services enables primary caregivers, professionals and all persons involved with the disabled child to work towards a common goal (McConachie & Pennington, 1997). Shared decision-making and joint responsibility should not only be viewed as impacting favourably on the CSD and the family. It also has positive outcomes for professionals, as energy is preserved, preventing “*burn-out*” (McDaniel *et al.*, 1990).

The specific skills are needed for collaboration are negotiation, team-building, joint decision-making, and problem-solving, but despite the fact that they are all learnable skills, they are not often addressed in teaching curricula (American Association of Colleges of Nursing, 1996). Although the BCIP does not focus on these skills, it sensitises community health nurses to the importance of collaboration and the fact that within a transdisciplinary approach one professional has to take primary responsibility for

service delivery. Collaboration is seen as one of the primary tasks of a community health nurses as described in the “*Standards for Community Health Nursing*” (cited in Wilkey & Gardner, 1999:307). It notes that “*community health nursing requires planning and sharing with others in the community to promote health for the community, family and individual. Through the collaborative process, the special abilities of others are used to communicate, plan, solve problems and evaluate services.*” The role of the nurse has thus shifted away from the role of servant to the medical profession towards the role of helper and partner of people and communities (Salvage, 1995).

Collaborative practice is not new but will continue to be promoted because it scrutinises costs and maximises efficiency of care.

## **2.5 SUMMARY**

The purpose of this chapter was to describe a transdisciplinary approach and its relation to CSDs. Transdisciplinary training was then linked to PHC with a communication orientation, highlighting the pillars of effective PHC service delivery (prevention, participation and protection) and a discussion of comprehensive and selective PHC approaches. Finally, transdisciplinary training was discussed in terms of the participants, the features and finally the approaches. Two specific approaches, namely multiskilling and collaboration that are used in the BCIP training, were highlighted.