

CHAPTER 1

INTRODUCTION TO THE STUDY

1.1 INTRODUCTION

The focus of this study is to determine the role, attitude, views and competence of the community nurse in integrating children with disabilities into the community. This chapter presents the background to the study, the purpose and significance of the study, research objectives, key concepts used and highlights Hildegard Peplau's nursing theory roles. The research methodology, and scope and limitations of the study are also briefly discussed.

The study identifies barriers to the integration of children with disabilities into the community as well as the strategies to address these barriers. The information is essential for the Mafikeng District Health Services to identify and develop strategies and infrastructures to integrate children with disabilities into the communities and thereby improve their quality of life.

1.2 BACKGROUND TO THE RESEARCH PROBLEM

1.2.1 Source of the research problem

The current situation which prompted the researcher to explore the role of the community nurse in integrating children with disabilities into the community is discussed under the following headings: (1) prevalence rates of children with disabilities, (2) attitudes towards persons with disabilities, (3) health care services for children with disabilities, and (4) the law and children with disabilities.

1.2.1.1 Prevalence rates of children with disabilities

This sub-section discusses the international and national prevalence rates of people with disabilities.

❖ **International prevalence rates of persons with disabilities**

Katzenellenbogen, Joubert and Abdool Karim (1997:224) reported that international prevalence rates of disability vary between 0,2% and 20%. A 1998 survey in Australia found that there were 3.6 million people with disabilities in that country, representing 19% of the Australian population (Evaluation of the Commonwealth Disability Strategy 1999:38–39).

In the United States of America (USA) about 17% of children under 18 years are reported to have a disability. Approximately 2% of school-aged children in the USA have serious developmental disabilities, such as mental retardation or cerebral palsy, and need special education services and supportive care (Developmental Disabilities among Children 1999:1).

According to Christianson (2000:3), in Africa, mild mental retardation was reported in 30 out of every 1000 rural Zambian children aged 2 to 9 years.

❖ **Prevalence rates of persons with disabilities in South Africa**

A survey by the South African Department of Health in 1999 reported that the prevalence of moderate and severe disability in South Africa is 5,9% of the total population. Of those who have a disability, 9,4% are children between 1 and 15 years, and 13,5% of the disabled population are under the age of 20 (Children in 2001:114).

Adults and children may be disabled by physical, intellectual or sensory impairment. Table 1.1 (page 3) shows the number and type of disabilities of children (0–18 years) with disabilities in South Africa, the North West Province, and the Mafikeng district from the 2001 census.

Table 1.1 Number of individuals (age 0-18) by disability

DISABILITY	SOUTH AFRICA	NORTH-WEST PROVINCE	MAFIKENG DISTRICT	% OF TOTAL MAFIKENG DISTRICT DISABILITIES
Sight only	10 8942	10 781	582	26%
Hearing only	94 564	5 888	323	14%
Communication	23 090	1 740	135	6%
Physical only	69 184	5 828	492	21%
Intellectual	73 458	5 434	313	13%
Emotional	46 826	3 654	296	12%
Multiple (combination of any of the above, for example mental and sight)	50 031	2 942	181	8%
Total	466 095	36 267	2 322	100%

(Source: South Africa 2001).

The discussion on childhood disability prevalence rates and the reported statistics in table 1.1 above, confirm that there is dire need for the issues of children with disabilities to be addressed, and that children with disabilities should be integrated in activities of the community.

1.2.1.2 Attitudes towards persons with disabilities

Negative attitudes of the community towards people with disabilities have been reported throughout the world. In Australia, Gething (1994:24) cites Yunker (1988) who points out that attitudes are comprised of positive or negative reactions towards an object, accompanied by specific beliefs that tend to impel the individual to behave in a particular way. Attitudes that interfere with equality and equity for children with disabilities should be identified and addressed by the community nurse.

This sub-section is discussed under (1) community attitudes, and (2) professional attitudes.

❖ *Community attitudes*

Gething (1994:22) found that in Australia the attitudes of the community towards people with disabilities were largely negative. A negative attitude is a barrier that interferes with quality of life and acceptance of people with disabilities as valued members of the community.

The attitude of the community towards children with disabilities has been found to be closely related to myths and superstitions regarding disabilities. Myths and ignorance about a disability often result in mothers of children with disabilities being ostracised by their partners, families and the community. This affects the non-disabled siblings, the survival of the family as a unit, and the meaningful development of the child with a disability (Children in 2001:113).

The community nurse should understand these historical beliefs, myths and superstitions regarding persons with disabilities in different communities, in order to deal with them with understanding.

To redress the negative attitudes towards people with disabilities that result from a lack of information and isolation, Stanhope and Lancaster (2000:629) are of the opinion that the community nurse should play a role in changing the attitudes of the community towards people with disabilities, enlighten others about this need, and help to obtain more appropriate health care services for persons with disabilities.

❖ *Professional attitudes*

The integration of children with disabilities into the community needs the team effort of professionals, especially community nurses, teachers and social workers. The attitudes of these professionals towards persons with disabilities will influence the integration process. This sub-section looks especially into the attitudes of community nurses and teachers.

Davies and Green (1998:97) cite Stephens and Braun (1980) and Gans (1987) who reported that international research on teacher attitudes towards children with special needs suggests that teachers in ordinary classrooms generally express negative attitudes towards inclusion.

In a qualitative study of 113 teachers from six local schools in the Cape Town area of South Africa, however, Davies and Green (1998:97) found positive attitudes towards integration. The study explored the attitudes of ordinary classroom teachers towards teaching learners with special educational needs. The findings revealed that some of the teachers had positive attitudes towards the inclusion of children with special educational needs. However, Davies and Green point out that the positive attitude of teachers were their reported attitudes and might not necessarily reflect their actual behaviour in real settings.

From the above, it is evident that the attitudes of the community and professionals play an important role in integrating children with disabilities into the community. The attitude of the community nurse to integrating children with disabilities into the community, and the community nurse' role in changing the attitudes of the community will therefore be explored in this study. In addition, access to health care services by children with disabilities also plays a major role in improving their health status and integrating them into society.

1.2.1.3 Health care services for children with disabilities

The developed and developing countries share the sentiment that providing appropriate health care services is essential to allow children with disabilities to develop to their full potential and access equal opportunities.

In South Australia, Brown (1999:i) recommended that the best situation for adults with disabilities is to ensure that there are effective services in the early years of their life.

In South Africa, the White Paper on an Integrated National Disability Strategy (South Africa 1997b:25) proposes that appropriate, accessible and affordable health services and equal opportunities be provided for people with disabilities.

In a study on childhood disabilities in the Bushbuckridge rural area in Mpumalanga Province, Kromberg, Zwane, Christianson and Manga (1997:13) also identified the need for children with disabilities to access a comprehensive health service.

As a resourceful person, it is important for the community nurse to be aware of available resources to advise the parents of children with disabilities appropriately. As a leader, the community nurse should be alert to a lack of resources for children with disabilities and advocate accordingly for these.

1.2.1.4 The law and children with disabilities

It is important to determine how the law protects adults and children with disabilities internationally and nationally. This sub-section highlights the legal framework as well as gaps in its implementation.

The United Nations Standard Rules on Equalisation of Opportunities for Persons with Disabilities, 1993 set out international standards for a national planning process. The Rules express the principles of full participation and equality for all people with disabilities (Do Disabled Children ... 2002:12).

Prior to 1994, the South African government also established positive mechanisms to encourage the full participation and development of adults and children with disabilities with the development of the Disability Rights Charter; and, since 1994, with the establishment of the Office on the Status of People with Disabilities, the adoption of the South African Constitution, and the White Paper on an Integrated National Disability Strategy. However, much still remains to be done if there is to be a society that truly integrates (and does not marginalise) people with disabilities (Department of Health 1999:9).

❖ The South African Constitution

The Constitution of South Africa Act, 108 of 1996 is the supreme law in South Africa, and makes it imperative that the rights of children with disabilities be recognised. Section 9 (3) of the Bill of Rights of the Constitution prohibits discrimination on the basis of age and disability (South Africa 1996:7, 13).

❖ **Convention on the Rights of the Child**

According to Article 23 of the United Nations Convention on the Rights of the Child (South Africa 1989:8), children with disabilities:

- ❖ should actively participate in the community activities
- ❖ should have access to a conducive environment to achieve the fullest possible social integration for individual development.

South Africa is a signatory to and has ratified the Convention on the Rights of the Child. This means that the state has obligations under the Convention to implement measures to promote the wellbeing and equality of children, including those with disabilities (DICAG Report 1998:17).

❖ **The Child Care Act, 74 of 1983 (as amended)**

The 1983 Child Care Act is the most comprehensive legislative measure aimed at protecting children in South Africa, including children with disabilities (DICAG Report 1998:17).

❖ **The White Paper on an Integrated National Disability Strategy**

The White Paper on an Integrated National Disability Strategy provides clear guidelines for the equalisation of opportunities for persons with disabilities, through enabling an integrated policy formulation, programme development and projects (DICAG Report 1998:17).

❖ **Gaps identified in implementing the legal framework**

A study conducted by the University of Pretoria in South Africa in 2002 (Do Disabled Children ... 2002:11) confirmed that there is much to be done to integrate adults and children with disabilities into society (Department of Health 1999:9). The study investigated access to health, education and social development services of children with disabilities living at Orange Farm (a peri-urban township situated

30 kilometres south of Johannesburg). The study revealed the discrepancy between policies and legislation regarding the rights of disabled children and service delivery (Do Disabled Children ... 2002:11).

The community nurse should be conversant with the laws and policies. The role of the community nurse in integrating children with disabilities into the community should be recognised as one of the major strategies to put into action the legislative issues to which the state is committed.

1.2.2 The research problem and background to the problem

The research problem is discussed under the following headings:

(1) Training of health professionals on disability, (2) accessibility and the environment, and (3) importance of integrating children with disabilities into the community.

1.2.2.1 Training of health professionals on disability

The importance of training professionals to manage children with disabilities is widely recognised. The Department of Health (2000:14) stresses the importance of trained health care workers and proposes that education and training programmes should aim to recruit and develop personnel competent to respond appropriately to the health needs of the population, including those of people with disabilities.

In most instances, parents of children with disabilities complain that professional service providers are the direct cause of keeping children with disabilities in the "back room" and not exposing them to the community. Parents complain of patronising and negative attitudes of service providers, poor assessment skills, prejudice and incompetence among professionals (DICAG Report 1998:18).

The Initial Country Report (South Africa 1997a:59) confirms the incompetence of professionals on disability, indicating that no mechanisms exist to ensure that students entering the health or teaching

professions acquire the skills and knowledge to equip them adequately to provide for children with disabilities.

In North-Western Ohio, USA, Dimmable, McInerney, William, Fox, Christine, Jochart and Kerry (1998:126) found that personnel were interested in providing care to young children with special needs, but cited a lack of knowledge as a barrier to providing inclusive care.

Similar findings were reported in South Africa. In a study undertaken in the Western Cape on teachers' attitudes to the integration of learners with special educational needs, teachers complained of the large classes and coping as a teacher without special training (Davies & Green 1998:100).

From the above, it is essential that community nurses receive appropriate training to improve their competence to manage children with disabilities and thus improve their quality of health, thereby facilitating their participation in community activities.

1.2.2.2 Accessibility and the environment

Accessibility has been and remains a major issue confronting people with disabilities and their ability to take part in society. The effect of not having an accessible environment was raised as important in relation to school attendance and work.

Difficulties with transport and the physical accessibility of buildings place further constraints on equal access for children with disabilities. The lack of communications in sign language for the deaf and material on cassette or in Braille for the blind is a particular problem (Department of Health 1999: 106-107).

The community nurse as a leader should be able to identify these possible barriers to integrating children with disabilities into the community and address these with the relevant stakeholders, such as welfare services and non-governmental organisations.

1.2.2.3 Importance of integrating children with disabilities into the community

Most studies reveal positive implications of integrating children with disabilities in educational settings. Johnson and Darrow (1997:174) cite Wang, Anderson and Bram (1985), who undertook a study to compare regular and special education placements. Johnson and Darrow found that:

- ❖ the academic and social performance of students with special needs who were in integrated settings were superior to those students educated in special classes
- ❖ the students who were included in regular classes on a full-time basis performed more successfully than their peers who were integrated on a part-time basis.

Gherardini (2000:62) supported Johnson and Darrow's (1997) positive findings in an address to delegates at the 7th World Down Syndrome Congress in Australia in March 2000, attended by the researcher. Gherardini pointed out that a national study by the Associazione Italiana Persone Down [in Italy] on school inclusion revealed that the inclusion of children with Down syndrome in mainstream education has had a long-term effect. The effect was that it improved the attitudes of the community towards children with Down syndrome (Gherardini 2000:62).

It is thus evident that children with disabilities will benefit from the integration process. The local media also advocate the benefits of integrating children with disabilities in the community. For example, the Sunday Times of 31 March reported that according to a US data analysis, the life expectancy of people with Down syndrome has doubled in fifteen years from 25 to 49 years because, among other things, they live in their communities (Double the life 2002:3) (see annexure H).

With regard to the increased life expectancy of children with Down syndrome, in Canada, Blais and Kerr (2000:80) point out that the life expectancy of individuals with Down syndrome is still shorter than that of the general population, but within the last decades has increased by more than 30 years.

It is therefore clear that the community nurse should enlighten families, communities, other health professionals and stakeholders on the importance of integrating children with disabilities into the community.

1.2.3 The problem statement

The problem that gave rise to this research is that there is a need to facilitate the social integration of children with disabilities into the community, and to improve the attitudes of the community and health professionals towards children with disabilities.

1.3 PURPOSE AND SIGNIFICANCE OF THE STUDY

Children with disabilities should be integrated into the community and actively participate in community activities for their individual development. The community nurse is of paramount importance in this process. Many people, including nurses, often have negative attitudes towards disabilities and are not aware of the significance of the integration process. It was therefore important to determine what role community nurses should play in this process, and whether they are competent to integrate children with disabilities into the community. No research findings could be located on this topic.

In view of the information obtained, the significance of the research was to recommend to the Mafikeng Health District that:

- ❖ programmes to facilitate the integration process and contribute to the development of children with disabilities be identified and developed
- ❖ the important role of the community nurse in integrating children with disabilities into the community be recognised
- ❖ the findings be communicated to the established Disability Desk in the Department of the Premier of the North West Province for consideration.

The following research questions were derived from the problem statement:

- ❖ What is the specific role of the community nurse in integrating children with disabilities into the community?
- ❖ How competent is the community nurse to integrate children with disabilities into the community?
- ❖ What are the attitudes and views of the community nurse to integrating children with disabilities into the community?
- ❖ What are the possible barriers to the integration process of children with disabilities into the community?
- ❖ What strategies should the community nurse use to deal with these barriers to the integration of children with disabilities into the community?

1.4 RESEARCH OBJECTIVES

The researcher proposed to achieve the following objectives with this study:

- ❖ To explore and describe the role of the community nurse in integrating children with disabilities into the community.
- ❖ To determine the competence of the community nurse to integrate children with disabilities into the community.
- ❖ To determine the attitudes and views of the community nurse on integrating children with disabilities into the community.
- ❖ To explore and describe ways in which children with disabilities can be integrated into the community.
- ❖ To identify barriers to the integration of children with disabilities into the community.
- ❖ To make recommendations on strategies that could be followed to facilitate the integration of children with disabilities into the community.
- ❖ To make recommendations for further research on the integration of children with disabilities into the community.

1.5 DEFINITION OF CONCEPTS

For the purpose of the study the following definitions and descriptions will apply:

1.5.1 Birth defects

Birth defects are any abnormality of body structure or function present at birth. They include inherited genetic disorders and non-genetic abnormalities. Some birth defects are visible at birth (for example, albinism and Down syndrome). Severe birth defects persist as a disability throughout life, reducing an individual's longevity and potential for full societal participation (Department of Health 2001: 2, 4).

Birth defects in this study refer to an abnormality of body structure or function that is recognised.

1.5.2 Child

According to the South African Constitution and the African Charter on the Rights and Welfare of the Child, a *child* is any person under the age of 18 years. According to the Convention on the Rights of the Child, a child is defined as any person under the age of 18 years (UNICEF Report 2002:13).

In this study, *child* refers to a person under the age of 18 years.

1.5.3 Community [health] nurse

Dennill, King and Swanepoel (1999:76) cite Hanlon who quoted Clark (1984) to define *community health nursing* as a field of specialisation within professional nursing and the broad area of organised public health practice.

In this study, a *community nurse* refers to all categories of nurses working in the clinics (registered nurses, psychiatric nurses, registered midwives, community nurses and enrolled nurses).

1.5.4 Community

Dennill et al (1999:84) cite Woelk's (1992:149) definition that a *community* is a group of people who live in a particular area and have shared values, cultural patterns and social problems, as well as a group awareness that facilitates the residents' interacting more intensely with each other than they would with outsiders.

In this study, *community* describes people in a particular area, who share and are aware of each other's values.

1.5.5 Disability

Collins English Dictionary (1991:447) defines *disability* as (1) "the condition of being unable to perform a task or function because of a physical or mental impairment (2) something that disables; handicap".

Disability refers to a number of different functional limitations occurring in any population. People may be disabled by physical, intellectual or sensory impairment, medical conditions or mental illness (WHO 1999: iii).

For the purpose of this study, *disability* refers to physical, sensory or mental disabilities, or the child may have difficulty in speaking, hearing or walking.

1.5.6 Integration or inclusion

In this study, *integration* and/or *inclusion* are closely related and sometimes used interchangeably.

❖ Integration

Collins English Dictionary (1991:802) defines *integration* as “the act of combining or adding parts to make a unified whole” and *integrate* as “to make or be made into a whole; incorporate or be incorporated”.

Social *integration* involves the full and active participation of children in their family environment, the community environment and all other environments they are exposed to (DICAG Report 1998:13).

❖ Inclusion

According to the Networker (1999:25) (Newsletter of the National Progressive Primary Health Care Network) *inclusion* means accepting a person with special needs as an equal human being and allowing him/her to develop to their full potential. Inclusion is based on respect for the dignity of a fellow human being, on a belief that all human beings are equal, although not necessarily the same, with unique and diverse qualities. The person with a disability does not have to change to fit in with society; society needs to change its attitudes and practices to accommodate the disabled person.

For this study, *integration* and *inclusion* mean to change the attitudes and actions of society, to accept children with disabilities as part of a family and community. This involves recognition of and intention to address the needs of children with disabilities in the family and the community.

1.5.7 Primary health care

The African National Congress (1994:20) defines *primary health care* according to the Declaration of Alma-Ata, as essential health care based on practical, scientifically sound and socially acceptable methods and technology, made universally accessible to individuals and families in the community, through their full participation, and at a cost that the community and the country can afford to maintain at every stage of their development in the spirit of self-reliance and self-determination.

Dennill et al (1999:2, 117) explain that the concept of *primary health care* encompasses a political philosophy that calls for radical changes in both the design and content of traditional health care services. It advocates an approach to health care based on principles that allow people to receive the care that enables them to lead socially and economically productive lives.

According to Alma-Ata, *primary health care* is a comprehensive approach to improving the health status of communities and individuals.

For the purpose of this study, *primary health care* refers to the comprehensive care given at family and community level to improve the quality of lives of children with disabilities.

1.6 THEORETICAL FOUNDATION OF THE STUDY

This study uses Hildegard Peplau's nursing theory of the interpersonal process as a theoretical framework to discuss the role of the community nurse in integrating children with disabilities into the community. According to Peplau, nursing can be viewed as an interpersonal process because it involves interaction between two or more individuals with a common goal (George 1995:50).

The interaction of the community nurse with the health system and families of children with disabilities was investigated, with the goal of integrating children with disabilities into the community.

The roles of the community nurse as a teacher, resource, counsellor, leader, technical expert, and surrogate in relation to integrating children with disabilities into the community are discussed in detail in chapter 2 of this study.

1.7 RESEARCH DESIGN AND METHOD

A brief overview of the research design and method used in this study is given in this section. A more comprehensive discussion is given in chapter 3.

The study used an exploratory, qualitative research design in the Mafikeng district, North-West Province. Focus group discussions and interviews with community nurses, clinic health managers and parents of children with disabilities were used as data-collection techniques.

Data was analysed qualitatively according to Tesch (1990:142-143) and the aid of the Qualitative Research and Solutions for Numerical Unstructured Data Indexing Searching and Theorising (QRS NUD*IST) computer programme (see annexure B: Coding System QRS NUD*IST).

1.8 SCOPE AND LIMITATIONS OF THE STUDY

The research was undertaken in the semi-rural area of the Mafikeng district, of the North-West Province. The generalisation of this study is limited, as all the information refers to the community nurses, clinic health managers and parents of children with disabilities in the Mafikeng district only. The focus group discussions were conducted in clinics and special schools. The sample size was relatively small, and any conclusions and generalisations that are reached will therefore only be applicable to this particular population and sample.

1.9 STRUCTURE OF THE DISSERTATION

Chapter 1 is an introduction to the study and presents the problem statement, research objectives, theoretical foundation, research design and method, and the scope and limitations of the study.

Chapter 2 discusses the literature review on the role of the community nurse in integrating children with disabilities into the community.

Chapter 3 describes the research design and method.

Chapter 4 presents the data analysis and research findings.

Chapter 5 concludes the study and makes recommendations for future research.

1.10 CONCLUSION

In this chapter, the researcher explained the significance of the study by describing the background to the study and the current situation of children with disabilities in the community.

In chapter 2, the literature review on the role of the community nurse in integrating children with disabilities into the community is discussed. The literature review is based on the objectives of the study as set out in this chapter and Peplau's nursing theory, whereby the community nurse assumes the roles of teacher, resource, counsellor, leader, technical expert and surrogate.