

## CHAPTER 2

### LITERATURE REVIEW

#### 2.1 INTRODUCTION

In this chapter the researcher discusses the literature review on the role of the community nurse in integrating children with disabilities into the community. Data required for the literature review was obtained from the University of South Africa (UNISA) library where a database search was done with reference to international and Southern African material, periodicals, books and the internet. Data was also collected from the Department of Health library, which provided information on the available health policies. Life experiences of children were noted from local newspapers and magazines to gain an insight into the practical situation of children with disabilities in South Africa.

The objectives of the study as set in chapter 1 were used as the basis for the literature review. The researcher explored integration into all spheres of life, but mostly referred to inclusion/integration into education, because of the availability of studies on inclusive education. The international and South African perspectives on the integration of children with disabilities are discussed in this chapter.

#### 2.2 PERSPECTIVES ON THE INTEGRATION OF CHILDREN WITH DISABILITIES

This section discusses international as well as South African and North West Province perspectives on the integration of children with disabilities.

##### 2.2.1 International perspectives on the integration of children with disabilities

The integration or inclusion of children with special educational needs has been highlighted in international literature since the late 1970s.

In the USA, Beckman , Barnwell, Horn, Hanson, Gutierrez and Lieber (1998:126) report that 1960s and 1970s witnessed an increasing emphasis on the inclusion of young children with disabilities in early education childhood settings with peers who did not have disabilities.

Beckman et al (1998:125) cite Shisler and Healer (1995), who researched teachers' views of inclusion, Buysse and Bailey (1993), who examined the developmental progress of children in inclusive settings, and Greenwood, Carter and Hall's (1988) study of the use of peers as intervention agents. Beckman et al state further that relatively few studies in early childhood focused on inclusion in other circumstances. In their view, this is unfortunate since "inclusion" is a concept that implies participation in a broad range of community settings.

In Africa, a UNICEF Report (1999:32) documents the successful integration of a 17-year-old blind girl from Tanzania into society as a result of being admitted to a local normal Uhuru primary school.

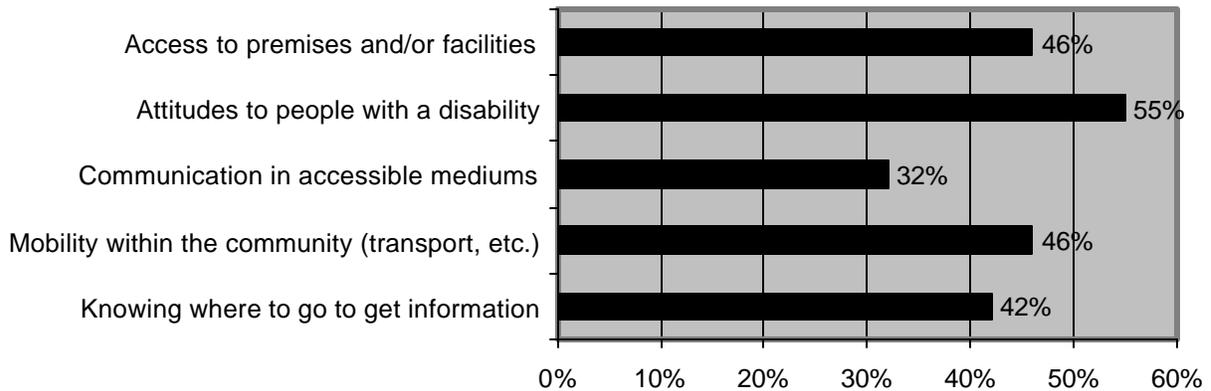
In Australia, Gething (1994:22) found that the attitudes of the community towards people with disabilities are mainly negative. A negative attitude is a barrier that interferes with quality of life and the acceptance of people with disabilities as valued members of the community.

Gething indicated further that negative attitudes towards people with disabilities are associated with the following reactions of non-disabled persons:

- ❖ experience of threat to security
- ❖ fear of the unknown
- ❖ feelings of vulnerability about the possibility of becoming disabled oneself
- ❖ perceived weakness of persons with disabilities.

The Evaluation of the Commonwealth Disability Strategy (1999:37) identifies attitudes as a barrier to participating fully in Australian life still faced by people with disabilities (see figure 2.1, page 21).

	Knowing where to go to get information	Mobility within the community (transport, etc.)	Communication in accessible mediums	Attitudes to people with a disability	Access to premises and/or facilities
Percentage of respondents	42%	46%	32%	55%	46%



**Figure 2.1**

***Main barriers faced by persons with disabilities in Australia***

(Source: Evaluation of the Commonwealth Disability Strategy 1999)

From figure 2.1, it is clear that the main barriers or obstacles to integration are attitudes towards persons with disabilities (55%), followed by access to premises and mobility in the community (both 46%).

It is essential that community nurses note these different perspectives to emphasise the importance of integrating children with disabilities into the community and to determine the success of and possible barriers to the integration of these children.

## **2.2.2 A South African perspective on the integration of children with disabilities**

South African views on the integration of children with disabilities is given in relation to education, the family and the community.

### ***2.2.2.1 Integration in education***

Davies and Green (1998:98) are of the opinion that the restructuring of education in South Africa after 1994 (Government of National Unity in place) presented an ideal opportunity to introduce a new approach on inclusive education for learners with special educational needs.

A qualitative study of 113 teachers from six local schools in the Cape Town area was conducted by Davies and Green (1998:97). The objective of the study was to explore the attitudes of ordinary classroom teachers towards teaching learners with special educational needs and discover the conditions under which they would be willing to do so.

The Cape Town study revealed that some of the teachers had positive attitudes towards the inclusion of children with special educational needs, and others were not in favour of inclusive education. These findings are discussed in detail under sections 2.6 (page 33) and 2.7 (pages 35) of this study on benefits and barriers with regard to the integration of children with disabilities into the community.

According to Davies and Green (1998:97) inclusive education in the South African context was also debated by Skuy and Partington (1990), Green (1991) and Kriegler and Farman (1994). However, Davies and Green point out that, historically, provision for special educational needs in South Africa has been unequal across racial groups. This situation led to inclusion only happening by default and a consequent absence of provision in most disadvantaged communities (Davies & Green 1998:98).

Davies and Green (1998:98) discuss the National Commission on Special Needs in Education and Training and the National Committee for Education Support Services' definition of an inclusive education as one where all learners have access within a single education system, that is responsive to diversity.

Furthermore, Davies and Green (1998:98) cite Rocher's (1993) study on inclusive education in KwaZulu-Natal, which found incredible dedication and optimism among the principals and teachers despite the many problems.

### **2.2.2.2 *Integration into the family and community***

Discrimination against children with disabilities appears to actually begin at home and in the communities. According to the White Paper on an Integrated National Disability Strategy (South Africa 1997b:2), the majority of people with disabilities in South Africa have been excluded from society, and have thus been prevented from accessing fundamental social, political and economic rights.

With reference to how South Africa recognises the rights of children with disabilities, see chapter 1, sub-section 1.2.1.4 (page 6), on law and children with disabilities.

This study focused on the role of the community nurse in facilitating social integration, which involves the full and active participation of a child with a disability in the family and community environment.

### **2.2.3 The North West Province perspective on the integration of children with disabilities**

The North West Province is committed to addressing the plight of adults and children with disabilities in the province. In 1998, the province adopted the White Paper on an Integrated National Disability Strategy (NW Adopts Integrated National Disability Strategy 1998:2). The Premier of the province expressed the political will to integrate persons with disabilities into society. A follow up Consultative Conference on Disability was held in 1999, in Mafikeng, to facilitate services to persons with disabilities in the Province (Consultative Conference on Provincial Disability 1999:18) (see annexure H).

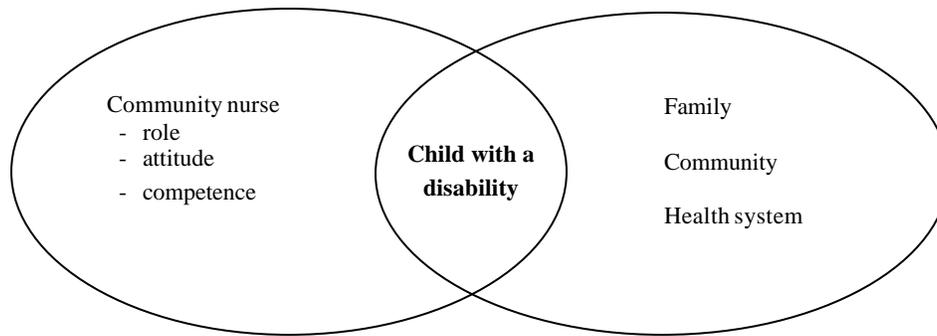
The challenge is to implement these policies and strategies. This study therefore explored the role of the community nurse in improving the plight of children with disabilities in the Mafikeng district, in view of these strategies and policies.

## 2.3 THE SPECIFIC ROLE OF THE COMMUNITY NURSE IN INTEGRATING CHILDREN WITH DISABILITIES

According to Hildegard Peplau's nursing theory, nursing can be viewed as an interpersonal process, which involves interaction between two or more individuals with a common goal (George 1995:50). Peplau describes the different nursing roles assumed in the various phases in the interpersonal relationship broadly as follows (George 1995:50-51):

- ❖ *Teacher.* The community nurse imparts knowledge concerning a need or interest.
- ❖ *Resource.* The community nurse provides specific, needed information that aids in understanding a problem or a new situation.
- ❖ *Counsellor.* Through the use of certain skills and attitudes, the community nurse assists children with disabilities and their parents in recognising, facing, accepting, and resolving problems that interfere with their ability to live happily and effectively.
- ❖ *Leader.* The community nurse carries out the process of initiation and maintenance of group goals through interaction.
- ❖ *Technical expert.* The community nurse provides physical care by displaying clinical skills in providing care.
- ❖ *Surrogate.* The community nurse takes the place of another.

The common goal in this study is to integrate children with disabilities into the community. The community nurse will interact with the health system, family and the community to integrate children with disabilities into the community. The specific role, attitude and competence of the community nurse to manage and integrate children with disabilities will determine the successful integration process of a child with a disability into the community (see figure 2.2 on page 25).



**Figure 2.2**

***Integration of children with disabilities into the community***

The interaction role of the community nurse as a teacher, resource, counsellor, leader, technical expert and surrogate is discussed according to Peplau's nursing theory (George 1995:50).

### **2.3.1 The community nurse as a teacher**

Smith and Maurer (1995:17) stress that because of working with people in various stages of wellness, the community nurse has special opportunities to foster human development and capabilities through client education.

Stanhope and Lancaster (2000:628) concur that the community nurse should be the one who provides sufficient knowledge to the parents of children with disabilities to enable them to decide on the most appropriate behaviour for their own needs, and the community with information about the causes and prevention of disabilities.

In their study on Orange Farm, the School of Health Systems and Public Health at the University of Pretoria examined the sense of despair and hopelessness felt by parents and caregivers of children with disabilities (Do Disabled Children ... 2002:11). The reasons for despair were that the parents and caregivers did not know what help is available, where to get help, and had no financial means to pay for transport to access points for help.

The teaching role of the community nurse entails educating the families, communities and other health professionals on the needs of children with disabilities.

### **2.3.2 The community nurse as a resource**

Smith and Maurer (1995:16) define referral as a process of directing to another source of assistance. As a referral agent, the nurse maintains current information about agencies whose services are of potential use to those who are disabled.

The community nurse should be able to provide information about the available resources to refer the parents of children with disabilities (Stanhope & Lancaster 2000:629). Smith and Maurer (1995:16) point out that the community nurse should learn a skill to assess the presence and quality of other health and social resources, such as welfare departments, churches and schools.

With regard to the role of the community nurse as a resource agent, Overeem and Webster (1997:i-iv) from the University of Botswana reported the case of a child diagnosed with Down syndrome whose parents were told by health professionals that the condition was not as bad as it seemed and things would get better. The parents returned home none the wiser and with no follow-up services or organisations to provide help and information.

It is evident that the community nurse should be conversant with disability conditions and educational, welfare and other essential services to assist the parents of children with disabilities to access these facilities.

### **2.3.3 The community nurse as a counsellor**

Stanhope and Lancaster (2000:628) view the counselling role of the community nurse as guiding the clients to learn to improve their problem-solving skills and explain further that the counselling of persons with disabilities and their families is an ongoing process. The basic goal of counselling is to

assist the client and the family in accepting the limitations of the disability and focusing on the individual's strengths and abilities.

According to Kromberg et al (1997:13), a genetic counselling team should visit rural areas. Kromberg et al's principle of outreach counselling is also supported in a national disability survey conducted in 1999 by South Africa (1999:157). Both direct (person with a disability) and proxy respondents (someone reporting on behalf of a person with a disability [a total of 1 703]) participated in the survey to answer what service they might need or have needed; the problems they had experienced with services in the past; and the place where the service was received. Table 2.1 below shows the number of persons with disabilities who indicated they had received a service.

**Table 2.1 Proportion of total population that received services**

TYPE OF SERVICE	MOST WHO RECEIVED SERVICE (%)
Health service	60
Assisting devices	18
Medical rehabilitation services	17
Traditional healer services	10
Welfare services	7
<b>Counselling services for the disabled</b>	<b>7</b>
Educational services	5
Vocational training services	1
<b>Counselling services for the family of the disabled</b>	<b>1</b>

The low level of counselling services for persons with disabilities (7%) and for the parents/family of children with disabilities (1%) is of great concern. These findings stress the importance of the counselling role of the community nurse in assisting parents of children with disabilities to cope with the condition. In addition, the WHO (1996:55) suggests that efficient and accurate genetic counselling in primary health care requires the development of educational material that can be handed out to patients, plus audio and videotapes, which may be even more useful than printed matter in a complex area.

The counselling role is important in that the community nurse should educate and be resourceful to the parents of a child with a disability. For the community nurse to provide appropriate counselling to

parents of children with disabilities, the necessary educational material should be available. This involves support from the authorities and a budget to have these educational materials.

#### **2.3.4 The community nurse as a leader**

Dennill et al (1999:63) and Stanhope and Lancaster (2000:629) emphasise the role of the community nurse as a leader for persons with disabilities. Dennill et al (1999:63) are of the opinion that because of the community nurses's unique position in the community and status at different levels of the health systems (primary, secondary and tertiary levels), a leadership role is assumed. As a leader, the community nurse should play a major role in changing the attitude of the community towards people with disabilities.

Stanhope and Lancaster (2000:629) believe that the community nurse should identify a need for changing the attitudes of the community towards people with disabilities, and enlighten others to this need.

Most authorities in the international health system agree on the important leadership role of the community nurse. Sines, Appleby and Raymond (2001:40) cite Kirsten Stalknecht, past-president of the International Council of Nurses (ICN), as stating: "It is clear that nurses and midwives are at the heart of most effective health care teams, especially the primary health care team. Using their varied capacities and expertise, nurses and midwives working in many different capacities will make a major contribution to health".

As a leader, and with the expertise knowledge the community nurse should facilitate change in the health structures, and advise the relevant authorities and stakeholders accordingly. This should be done to integrate persons with disabilities into the health system and in the community.

### **2.3.5 The community nurse as a technical expert**

The community nurse should be able to identify individuals with disabilities who need services that they are not currently receiving. The focus of this role should be monitoring the health status of the entire group, or communities (Stanhope & Lancaster 2000:629).

Technical expertise is also related to the competence of the community nurse to break the news to parents, after the delivery of a child with an abnormality. Kerr and McIntosh (1998:229) are of the opinion that information given and attitudes conveyed by health professionals during the critical early weeks following the birth of a baby with a disability are significant.

### **2.3.6 The community nurse as a surrogate**

As a surrogate, the community nurse assumes an advocacy role. Advocacy is an instance of speaking or writing on behalf of someone else, and using persuasion in support of another person. This requires the skill of assertive communication channels within, and among, organisations (Smith & Maurer 1995:17).

According to Stanhope and Lancaster (2000:629) one of the potential problems with this role, however, is that the community nurse may unintentionally foster excessive dependence by individuals, families or other groups.

The observational and communication skills of the community nurse are important to talk on behalf of children with disabilities and their parents. At the same time, the community nurse should be alert to excessive dependence by the families of children with disabilities (Stanhope & Lancaster 2000:629).

## 2.4 COMPETENCE OF THE COMMUNITY NURSE TO INTEGRATE CHILDREN WITH DISABILITIES INTO THE COMMUNITY

The competence of professionals to include children with disabilities in an ordinary class has been found to relate to their attitudes towards inclusion.

Davies and Green (1998:97) point out that attitude towards inclusion is closely tied to the teacher's feelings of competence and effectiveness in educating the children with special needs in an ordinary classroom.

They go on to cite Mitler (1995:108), who indicated that progress towards inclusion involves political will, effective teacher education and a new approach to partnerships with parents, the community, organisation and curriculum.

In a study of 100 teachers from Gauteng and the Western Cape on understanding inclusion, Eloff (2001:16-17) established that aspects that were particularly troublesome to inclusive education were:

- ❖ behavioural problems of the children
- ❖ professional competency regarding inclusion
- ❖ communication with parents.

A lack of relevant training is regarded as a major barrier to integrating children with disabilities into education. Cole (1999:217), from Edith Cowan University in Australia, reported that teachers who were not in favour of the inclusion model argued that substantial costs would be involved in arranging full inclusion, and that regular class teachers are not trained to deal with students with disabilities and not able to provide the appropriate services.

This is consistent with the findings of a study conducted in the Western Cape, where the most prominent concerns raised by teachers who were not in favour of the inclusion of children with

disabilities in the ordinary classroom were class size, lack of skills and the additional demands on teachers' time and energy (Davies & Green 1998:99).

With a view to improving the competence of the nurse to care for persons with disabilities in the community, the School of Nursing at the University of Natal conducted a survey in 1999 to develop basic curriculum guidelines for nursing and midwifery education in the region. Some of the problems identified in the survey were that nursing and midwifery education and practice were still mainly hospital based, with very few nursing schools having moved to a community-based or community-focused approach.

Guidelines were developed which recommended, among other things, that basic nursing and midwifery programmes prepare a nurse generalist and midwife who can work in a community or hospital setting and can deal with mental and physical health problems (Uys 2000:6-7).

Supporting the importance of the appropriate training of personnel, the Department of Health (2000:14-15) proposes that:

- ❖ education and training programmes should aim to recruit and develop personnel who are competent to respond appropriately to the health needs of the population, including those of people with disabilities.
- ❖ training should reflect disability as a human right and development issue by targeting people with disabilities and their families.

The argument on competence confirms that the relevant training and attitude of the community nurse will determine the success of integrating children with disabilities into the community.

## 2.5 ATTITUDE OF THE COMMUNITY NURSE TO THE INTEGRATION OF CHILDREN WITH DISABILITIES INTO THE COMMUNITY

To a large extent, the attitude and views of the community nurse will determine the success of integrating children with disabilities into the community.

With reference to education, Davies and Green (1998:97) cite Baker and Gottlieb (1980), who clearly indicated that teachers' attitudes are expected to influence the extent to which children with disabilities become not only physically integrated, but integral members of regular classes, benefiting academically, socially and emotionally from the experience.

Stoiber, Gettinger and Goetz (1998:121) found positive beliefs of education practitioners towards inclusive education. Like Davies and Green, Stoiber et al (1998:121) alluded to the fact that the positive beliefs of practitioners influence what Weiner (1986) calls a "norm to be kind" to those with limitations.

In South Africa, the University of Pretoria conducted a study in 2002 to investigate access to health, education and social development services of children with disabilities living in Orange Farm, a peri-urban township situated 30 kilometres south of Johannesburg (Do Disabled Children...2002:12). The caregivers of 156 children with disabilities were interviewed. The study found that among the reasons given by the parents of why children with disabilities do not have access to education, health and social services, were the negative attitudes towards disability and a lack of information on the part of the service providers.

Gething (1994:24) cites Leonard and Crawford (1989) who state that attitudes may be expressed on two levels: societal and personal. Attitudes on a societal level relate to issues such as how people with disabilities should be treated by society and the rights of people with disabilities. Attitudes on a personal level refer to a person's own reactions to people with disabilities.

From this, it is evident that the community nurse's own reaction to children with disabilities will influence the process of integration. As a leader and teacher, the community nurse should positively

influence the attitudes of the community to children with disabilities. (See figure 2.1 (page 21) showing the attitudes of the community as a major barrier to the integration of persons with disabilities into the community).

Buysse, Wesley and Keyes (1998:170) cite Smith and Rose (1993) who found that issues related to personnel training, as well as attitudes and values, were distinctive barriers to inclusion. Buysse et al (1998:171) also refer to a national survey in the USA that found that attitudes about inclusion were problematic in placing preschoolers with disabilities in normal settings. The survey indicated that the following respondents identified attitudes to inclusion as problematic:

- ❖ 65% of local directors of special education programmes
- ❖ 67% of preschool special education coordinators
- ❖ 100% of parents.

The positive attitudes of community nurses to integrating children with disabilities into the community will benefit these children socially and emotionally.

## **2.6 BENEFITS OF INTEGRATING CHILDREN WITH DISABILITIES INTO THE COMMUNITY**

The benefits of integrating children with disabilities are given from the perspective of (1) the child with a disability, and (2) the child with no disability and the professionals. Consideration is also given to the positive implications and the reported negative implications of integrating children with disabilities into the community.

### **2.6.1 Benefits for the child with a disability**

Most studies agree on the positive implications of integrating children with disabilities into different settings (Gherardini 2000:62; Johnson & Darrow 1997:174). Wang, Anderson and Bram (1985) (in Johnson & Darrow 1997:174) found that placing learners with special needs in an ordinary school

promotes their integration into society and facilitates skills development (see chapter 1, section 1.2.2.3, page 10).

An UNICEF Report (1999:32) documented the successful integration of a 17-year-old blind girl from Tanzania into society because of admission to a local normal Uhuru primary school.

Community nurses should note these positive implications to use as principles to encourage the integration of children with disabilities into the community.

With regard to negative implications, in a study in the Western Cape, in South Africa, Davies and Green (1998:100) noted that inclusive education could have negative implications. The findings revealed that teachers who were not in favour of inclusive education raised concern that the child with special educational needs:

- ❖ would distract the attention of the rest of the class
- ❖ might be teased and feel unhappy.

## **2.6.2 Benefits for the community**

This section discusses the benefits for the non-disabled persons when a child with a disability is placed in an inclusive education system.

Logan, Diaz, Piperno, Rankin, MacFarland and Bargamian (1995:42) found the following benefits to the children with no disabilities and the teachers in a Georgia school system that included students with disabilities in the regular classroom:

- ❖ The presence of students with a disability sparked an understanding and acceptance of difference.
- ❖ Teachers recognised the value of inclusion because of its power as an effective instructional practice.

- ❖ As advocates for their friends with disabilities, the non-disabled students were inspired to reach out to the community and the state.
- ❖ The non-disabled students developed empathy and compassion, qualities that would help in school and in life.

From the above, it is evident that the person who will benefit the most from the integration process is the child with a disability. Other children will benefit, too, as well as the professionals and the community. A better understanding of the psychosocial implications of disabilities will be developed in the community. The community nurse and other professionals will also improve their skills to care for children with disabilities, if these children are included in the basic services.

Children with disabilities should therefore be integrated into the community for the benefit of all. It is essential for the community nurse to be conversant with these findings in order to advocate the integration of children with disabilities into the community.

## **2.7 BARRIERS TO THE INTEGRATION OF CHILDREN WITH DISABILITIES INTO THE COMMUNITY**

Several barriers have been identified to the integration of people with disabilities into the community. The main barriers to the integration of persons with disabilities into the communities are problems regarding preparations for integration, concerns about the adequacy of resources, and potential conflicts among various stakeholders (Buisse et al 1998:170).

This section classifies barriers identified in (1) inclusive education, and (2) the community.

### **2.7.1 Barriers identified in inclusive education**

Buisse et al (1998:170) conducted a study in the USA to assess perceived barriers associated with early education childhood inclusion. The study found the following barriers to inclusive education:

- ❖ Early childhood programme quality barriers, which included lack of personnel training, lack of teacher planning time and inadequate classroom facilities.
- ❖ Community resource barriers, which included lack of transportation.
- ❖ Barriers associated with co-ordinating and integrating services for young children with disabilities and their families.

These findings are consistent with Davies and Green's (1998:100) observations that teachers who were not in favour of inclusive education complained:

- ❖ that too much time and work would be involved in teaching children with special educational needs
- ❖ of high numbers pupils in their classrooms
- ❖ of a fear of neglecting the rest of the class if they had to give individual attention to the learners with special educational needs.

### **2.7.2 Barriers identified in the community**

The attitudes of the community and professionals towards persons with disabilities as possible barriers to the integration process of persons with disabilities into the community are discussed in detail in and section 1.2.1.2 (page 3) and section 2.5 (page 32) .

In 1998, a study on disability was commissioned by the Office of Disability in Australia. Stakeholders, service providers and people with disabilities identified the following barriers to the integration of persons with disabilities (Evaluation of the Commonwealth Disability Strategy 1999:38–40):

- ❖ a lack of awareness of the needs of people with disabilities
- ❖ a lack of funded services
- ❖ no physical access to buildings
- ❖ fear and ignorance in the community
- ❖ overlooking the talents of people with disabilities
- ❖ ethnicity, culture and language

- ❖ literacy and lack of networks for information.

The lack of an accessible environment as a possible barrier to integrating children with disabilities is discussed in chapter 1 (see section 1.2.2.2, page 9).

With reference to the above barriers, the community nurse should be alert to these obstacles and identify strategies to address them.

## **2.8 THE COMMUNITY NURSE ADDRESSING BARRIERS TO THE INTEGRATION OF CHILDREN WITH DISABILITIES**

The community nurse should use Peplau's nursing theory roles as discussed in section 2.3 (page 24) to address the barriers to the integration of children with disabilities into the community. The barriers to the integration process will be discussed under the following headings: (1) role of the family (2) role of the community, (3) role of education, (4) accessibility to basic services, and (5) cost of disability programmes.

### **2.8.1 Role of the family**

Brown (1999:10) emphasises that families should recognise that inclusion is not just a matter of inclusion in schools, but is an issue of inclusion in the home and community. He cites Timma and Brown (1996) who indicated that children with disabilities are required to go to bed much earlier than children that are not disabled; have fewer friends and are treated as people quiet and 'tucked away', whether tucked away in bed, home, special schools or in a tightly circumscribed community; are made cosy and comfortable, rather than allowed opportunities for exploration and stimulation. Timma and Brown highlighted that exploration and stimulation play an important role in the biological development of the brain, and therefore the social and cognitive performance of children with disabilities as they grow into adulthood.

Health, Down Syndrome (1995:58) describes the important role of the family as a life experience in Mafikeng, North-West Province. According to the magazine article, an eight year-old girl with Down syndrome is happy and fulfilled, able to do things herself, answer the phone properly and even take messages. The girl's mother emphasised that it is important not to hide children with Down syndrome, but to shower them with love and stimulation from an early age to improve their quality of life (see annexure H).

Swick (1997:152) in South Carolina, USA found that families provide the foundation for a caring society, and strong families begin with the realisation that what they are about is valued and supported by the community. Swick emphasises that parental leadership training is essential to improve parental skills. Swick states further that with a supportive environment, parents can take on leadership roles in developing family networks and supports that ultimately strengthen the total community.

The community nurse should collaborate with parents, identify the needs of the family, provide a supportive environment, and work with the parents as a team to integrate children with disabilities into the community.

## **2.8.2 Role of the community**

Beckman et al (1998:126) believe that studying community inclusion is important because communities are powerful contexts for inclusion. Beckman et al (1998:126) cite Turnbull, Turnbull and Blue-Banning (1994) who maintain that, to be fully included, persons with disabilities need to establish relationships that have the potential for long-term friendship and support.

According to Beckman et al (1998:127), the classroom is an important inclusion community setting, but participation outside the classroom is as important.

Beckman et al (1998:125) also found that families of children with disabilities and those without disabilities stressed the importance of having a sense of community because it created a feeling of support, connection and friendship, and was associated with social participation.

Sines et al (2001:234) found that it is difficult to be clear about the expectations of the public in relation to services for people with learning disabilities. These authors indicate that public attitudes towards people with learning disabilities have improved, with greater willingness to accept people with learning disabilities, and support their use of community-based services. At the same time, however, there is growing evidence to show that people with learning disabilities continue to be subjected to intimidation, bullying and discrimination (Sines et al 2001:234).

Community members also identified the need to integrate children with disabilities in the community. Kambule (2002:10) pointed out that society needs to be sensitive and helpful to people with disabilities. Kambule appealed to all South Africans to join hands to address the challenges of integrating people with hearing impairment into the community (see annexure H).

From the above, it is clear that the community also plays a significant role in integrating children with disabilities.

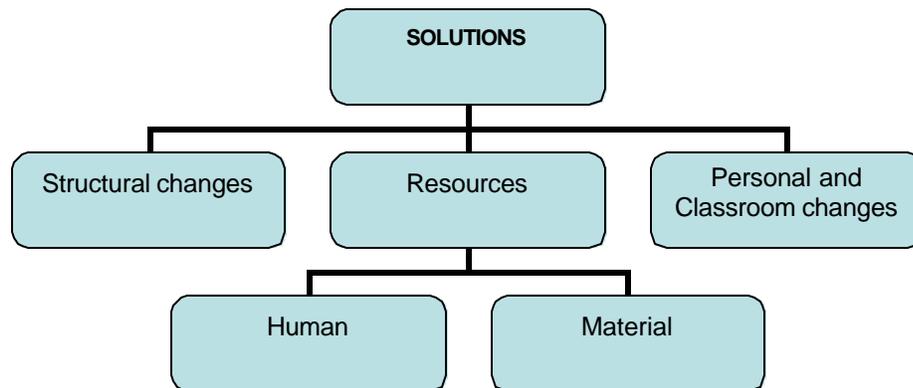
### **2.8.3 Role of education**

Schools are among the places where children learn key skills and gain knowledge about the world, and are 'socialised' to be aware of society's future expectations of them as citizens (UNICEF Report 2002:27).

Davies and Green (1998:97) refer to the important role of education in integrating children with disabilities into the community and cite Paul; Turnbull and Cruikshank; Apter; and Drew and Watts, who believe that the education of children with special needs in a normalised learning environment should be consistent with their needs.

According to Davies and Green (1998:97) inclusion in education promotes integration into society and facilitates the skills development of children with special needs (see section 2.2.2.1, page 22). In their study of Cape Town teachers not in favour of inclusive education, Davies and Green (1998:98) further asked these teachers to suggest solutions to the problems they identified with inclusive education.

Davies and Green (1998:100) divided the solutions suggested by the teachers into three categories, namely (1) structural changes (decreased class sizes); (2) resources (human and material resources, remedial teachers, specialist assistance for the teacher and child, parental involvement, teacher aides, teacher aid teams and apparatus); and (3) personal and classroom changes (skills training, time to work with the child, different ability groups, give love and attention, provide social skills training, and educate the class about the child with a disability). Figure 2.2 below reflects the categories of solutions suggested by the teachers to deal with the inclusive education problems.



**Figure 2.3**

***Solutions suggested by the teachers to address the inclusive education problems***

The collaborative and leadership role of the community nurse is therefore crucial to recognise how education can integrate a child with a disability into the community and possible strategies to tackle related problems.

#### **2.8.4 Accessibility to basic services**

Section 27 of the South African Constitution guarantees everyone the right of access to health and welfare services.

Sines et al (2001:238) point out that the existing health services in many areas continue to be characterised by either perceived 'medical or social' models of care. Future services will be required to become more holistic and health focused, and the emphasis will be on comprehensive holistic assessment of an individual's abilities and needs while giving recognition to their social circumstances.

According to Sines et al stress a move towards inclusive services has implications for a community nurse, who has a role in facilitating access for people with learning disabilities to a range of inclusive services, particularly health services.

Transformation of health services depends on restructuring, re-organising and redressing past inequalities (South Africa 1997b:53). It is therefore crucial that special efforts be made to recognise the important role of the community nurse in transforming health services to redress past inequalities, and to reach out to children with disabilities.

To emphasise the importance of accessing basic services, the University of Pretoria (Do Disabled Children ...2002:11) (see under section 1.2.1.4, page 7 and section 2.3.1, page 25) found the following:

Reasons for lack of access to education, rehabilitation and care dependency grants, given by the parents:

- ❖ *Lack of information* on the part of parents and caregivers – parents do not know what help is available and where to get help.
- ❖ *Poverty*. Parents do not have the financial means to pay for services, for example, to pay for transport to access hospitals and social work offices.
- ❖ *Transport*. The special schools and rehabilitation services are outside of Orange Farm. Transport is expensive and the children are too heavy to carry.
- ❖ *Lack of information on the part of service providers*. Parents are given incorrect information, or information is communicated badly.
- ❖ *Attitudes towards disabilities* on the part of the service providers.

- ❖ *Fragmentation of services.* There is little evidence of active cooperation between the Health, Education and Social Development Departments, and the community-based organisations of persons with disabilities.

Despite the constraints identified by the parents, the Department of Health in South Africa is committed to providing accessible and affordable health services for adults and children with disabilities. This is evidenced in a recent announcement by the Minister of Health that persons with disabilities can access health care services in the public health facilities free of charge (Department of Health 2003:8) (see annexure H). The importance of children with disabilities accessing appropriate health care services is also discussed in section 1.2.1.3 (pages 5).

The community nurse should use Peplau's interaction role to negotiate with all the relevant stakeholders to improve the access of children with disabilities to basic services as entrenched in the Constitution of South Africa, the Convention on the Rights of the Child, and other related policies and legislature.

### **2.8.5 Cost of disability programmes**

There are different views on the budget for disability programmes. The DICAG Report (1998:39) proposes an inclusive budget. According to the report, redress and creating equal opportunities for children with disabilities should be priorities in government spending if the rights of children with disabilities as provided for in the Convention on the Rights of the Child are to be realized. The report emphasises that funding aimed at overcoming barriers to survival and development for children with disabilities should therefore form an integral part of national programmes of action for children with disabilities.

The high costs involved in caring for a child with a disability are also debated. According to the Department (2001:55-56), approximately 150 000 of the children born in 1996 will present with a significant genetic disorder or birth defect by the age of five years, and it is therefore expected that the costs for the care of children with genetic disorders will be substantial.

The Department estimates further that the cost of caring for a child with Down syndrome is approximately R124 000,00 per patient per annum (for example, for physiotherapy, speech therapy, occupational therapy, holistic home programmes, heart sonars, operations, medication and blood tests).

Honig (1997:94) contends that if there is too much emphasis on provision of specialised services, such as occupational therapists and physical therapists, when planning an integrated environment for young children with special needs, the programme may lose sight of the fact that providing a rich, loving, learning experience for these young children is the main objective. According to Honig, young children learn best in an emotional climate that gives them security and affirmation.

The community nurse should be able to identify factors that will ensure security and affirmation for children with disabilities in providing an integrative health care service and should be aware of the costs involved.

## **2.9 CONCLUSION**

In the literature review, the researcher could find little or no research to date internationally and in South Africa that explored the role of the community nurse in integrating children with disabilities into the community. The focus of previous studies was on education and integration.

The literature review reveals that the successful integration of children with disabilities into the community depends on a number of factors, including the role of the families and communities, as well as the attitude and competence of the community nurse.

Chapter 3 discusses the research design and methodology.