

CHAPTER 4

DATA ANALYSIS AND RESEARCH FINDINGS

4.1 INTRODUCTION

Chapter 3 described the research design and methodology of this study in the Mafikeng district. This chapter discusses the data analysis and the research findings.

The research findings are discussed with reference to the research problem outlined in chapter 1 and the literature review in chapter 2 to highlight similarities and different findings. The research findings were also based on the following objectives of the 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 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.

4.2 THE RESEARCH SETTING

This section describes the clinics and staff where data was collected as well as the disability profile in the Mafikeng district.

4.2.1 Clinics and the research participants

An overview of the background of the clinics where data was collected, and the research participants is given in this sub-section. This information was provided by the clinic health managers during the interviews.

Data was collected from eight of the clinics of the Mafikeng semi-rural area (see chapter 3, under section 3.3.2.3, page 52). Four focus group discussions with community nurses were held and the clinic managers of the clinics were interviewed.

The respondents were composed only of the black nurses and clinic managers, and were predominantly Tswana-speaking. The parents were all black parents and also Tswana-speaking. Tswana is the most common ethnic group in the North West Province. It may be assumed that the community nurses and parents belong to a common value system, and therefore have a good understanding of issues in the Mafikeng district.

Table 4.1 (page 80) indicates the number of patients seen in the respective clinics per month, number of nurses allocated at the clinics the month that data was collected (June 2003), and number of nurses who attended a course in genetics (one-week course). Figure 4.1 (page 80) is a bar graph representation of table 4.1. This information served as a reference in the data analysis.

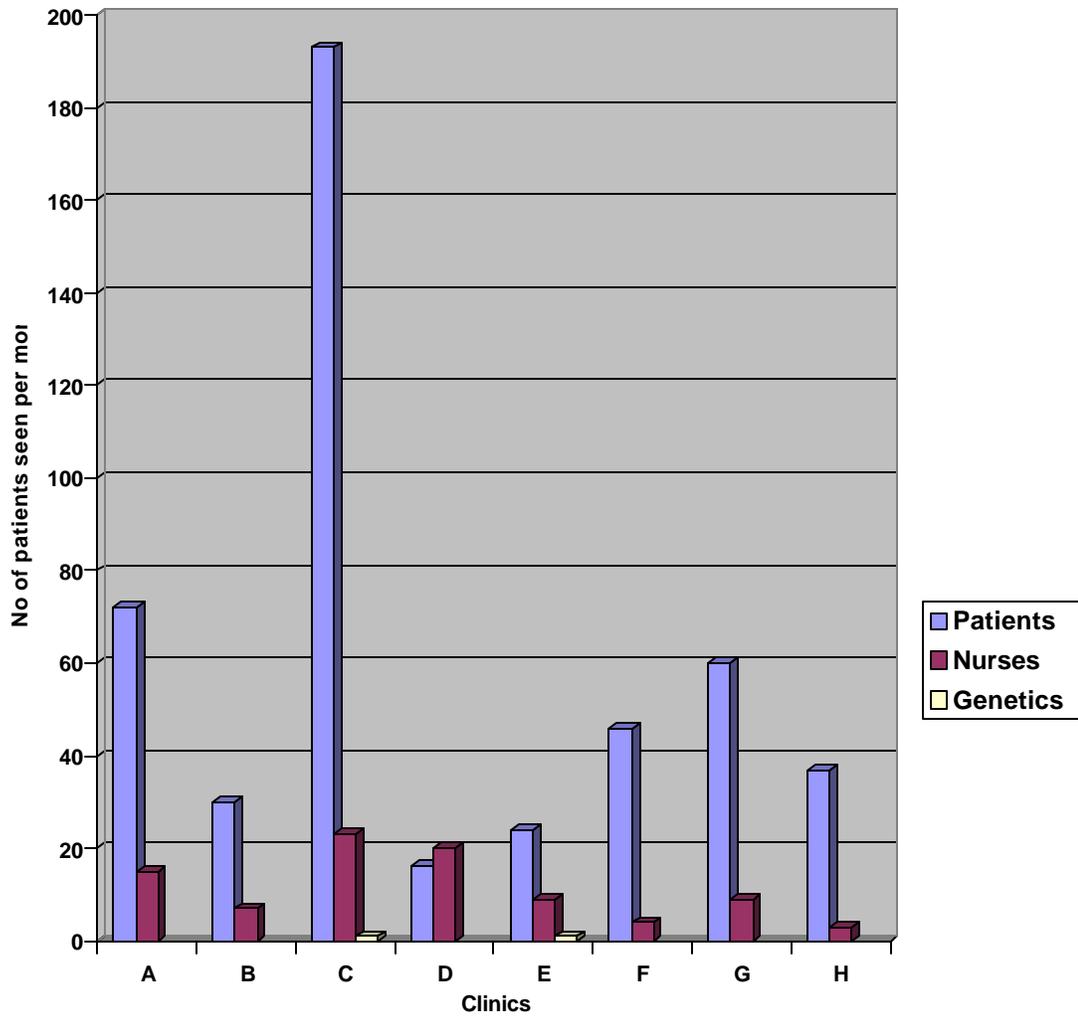


Figure 4.1
Bar graph indicating background information of the clinics

Table 4.1 Background information on the clinics where data was collected

	CLINIC A	CLINIC B	CLINIC C	CLINIC D	CLINIC E	CLINIC F	CLINIC G	CLINIC H
Number of patients seen per month	3 600	1 500	9 596	780	1 200	2 300	3 000	1 825
Number of nurses placed in the clinic	15	7	23	20	9	4	9	3
Number of nurses- attended genetic course	0	0	1	0	1	0	0	0

In figure 4.1, a scale of 1:50 was used for the number of patients seen per month as follows:

Clinic A : 3 600 ÷ 50	=	72
Clinic B : 1 500 ÷ 50	=	30
Clinic C : 9 596 ÷ 50	=	193
Clinic D : 780 ÷ 50	=	16
Clinic E : 1 200 ÷ 50	=	24
Clinic F : 2 300 ÷ 50	=	46
Clinic G : 3 000 ÷ 50	=	60
Clinic H : 1 825 ÷ 50	=	37

4.2.2 Profile of disability in the Mafikeng district

The information on the common disabilities or birth defects seen in the Mafikeng district was provided by the community nurses, clinic health managers and parents.

The themes and categories of parents' understanding of the child's condition with a disability are reflected in figure 4.2 (below) and table 4.2 (page 82).

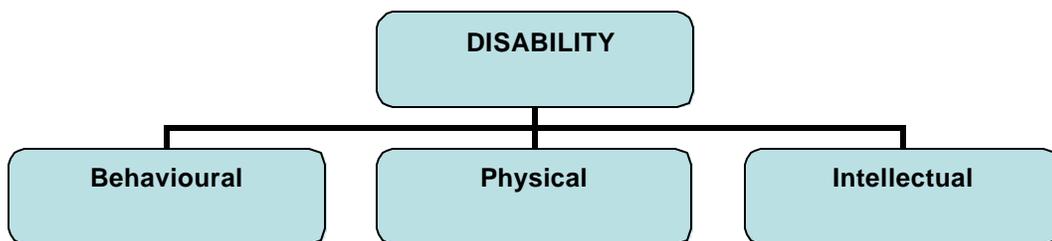


Figure 4.2

Visual presentation of themes of parents' understanding of the child's condition with a disability

The data analysis indicated that the parents were observant of their children with disabilities and described the condition in such a way that it could be classified under the themes: behavioural, physical and intellectual. The specific understanding of each theme as described by the parents is reflected in table 4.2 (below).

Table 4.2 Themes and categories of parents' understanding of the child's condition with a disability

THEME	CATEGORY
Behavioural	Mood swings Naughty Aimless wandering Bullying Short temper
Physical	Tremors Limping – due to short leg Whiteness in eyes
Intellectual	Slow learner Difficulty in learning Incoordination Difficulty in writing Confusion Forgetfulness Speaks slowly Slow thinker

Information on the specific diagnosis of disabilities was provided by the community nurses and clinic health managers. Table 4.3 (page 83) illustrates the classification of disabilities in the Mafikeng district. The classification was noted in terms of how many of the four focus group discussions of the community nurses identified the condition as common in that particular community.

It was not possible to establish exactly how many of these cases were seen at the clinics. However, table 4.3 indicates that the three most common disabilities seen in the Mafikeng district are mental retardation, Down syndrome and albinism.

Children with mental retardation and Down syndrome may present with behavioural and intellectual disability. The diagnosis given by the community nurses therefore supports the parents' descriptions of the children's condition with a disability as behavioural and intellectual, as reflected in figure 4.2 (page 81) and table 4.2 (page 82).

Table 4.3 Classification of disability by diagnosis

DIAGNOSIS	MENTIONED IN:
Mental retardation	All 4 focus groups
Down syndrome	all 4 focus groups
Albinism	all 4 focus groups
Spina bifida	2 focus groups
Hydrocephalus	2 focus groups
Cleft palate	2 focus groups
Club foot	1 focus group
Achondroplasia	2 focus groups
Microcephaly	1 focus group
Deaf	1 focus group
Epilepsy	1 focus group
Physical disability	2 focus groups

Data from the parents and the community nurses about the disabilities in the Mafikeng district is in line with statistics provided in Statistics South Africa (see table 1.1, page 3 and annexure A).

Mental retardation as a common disability in the Mafikeng district is in line with the prevalence rate of mental retardation reported by Christianson (2000:3) in Africa, that is 30/1000 in rural Zambia of children aged 2 to 9 years (see under section 1.2.1.1, page 2).

4.3 DATA ANALYSIS STRATEGY

Tesch's (1990:79) content analysis procedure was used as the data analysis strategy for this study. The text was classified into content categories. According to Tesch (1990:79), a basic procedure in

content analysis is to design categories relevant to the research purpose and to sort all occurrences of relevant words or other recording units into categories.

The data classification procedure is discussed in detail in section 3.5.2 (page 65). The transcription process and coding system are briefly outlined below.

4.3.1 Transcription

The qualitative data obtained from the focus group discussions with the community nurses and parents of children with disabilities and the interviews with the health managers were transcribed, and prepared in an accessible visual written presentation using the MS Word computer programme. This was done to obtain an overall picture of the data and consider the observations in retrospect.

4.3.2 Coding and categorisation of data

The QRS NUD*IST computer programme was used to develop codes and categories of the data. Data were coded and categorised until saturation occurred, and were developed into themes and sub-themes (see annexure H). This chapter presents the themes of the data analysis and discusses the research findings of this study.

4.4 RESEARCH FINDINGS

The research findings are discussed in the light of the research objectives and according to the themes and sub-themes that emerged from the data analysis. The research findings were constantly compared with those of previous studies, and responses of the respondents are quoted in support of the findings (Holloway & Wheeler 2002:274).

4.4.1 Specific role of the community nurse in integrating children with disabilities

The following are some of the questions asked to the research participants to achieve this objective (see annexure C).

Questions to parents

Q: Has the community nurse been helpful when you brought your child with a disability to the clinic? In what way?

Tswana: *A go nale thuso e e maleba e o ntseng o e bona go mooki fa o tlisa ngwana wa gago yo o golafetseng mo kliniking?*

Q: How can the community nurse influence society to accept your child with a disability?

Tswana: *Fa o akanya, mooki wa mo kliniking a ka thusa jang gore ngwana wa gago yo o golafetseng a amogelwe senlthe ke baagisane kampo a amogelwe mo setshabeng?*

Questions to community nurses

Q: How do you manage children with disabilities brought to the clinic?

Q: Can you remember cases of children with disabilities you have seen in the clinic? Please elaborate.

Peplau's roles of the community nurse as a teacher, resource, counsellor, leader, technical expert and surrogate (see chapter 2, section 2.3, page 24) were used as a basis to analyse the responses of the research participants.

The data analysis established that both the community nurses and parents recognise Peplau's roles of the community nurse. Table 4.4 (page 86) represents the parents' understanding of the role of the community nurse.

Table 4.4 Parents' perceptions of the role of the community nurse

ROLE OF COMMUNITY NURSE AS A	ACTIVITIES DESCRIBED
Teacher	<ul style="list-style-type: none"> * Raise awareness on disabilities * Give health education * Engage in talk shows * Call meetings in community * Encourage celebrating disability days * Encourage those hiding to come out in public * Visit schools * Address congregation in church
Resource	<ul style="list-style-type: none"> * To get help e.g. application for grants * To be referred when need arises
Counsellor	<ul style="list-style-type: none"> * Give counselling to the parents and extended family
Leader	<ul style="list-style-type: none"> * Involve – community and schools
Technical expert	<ul style="list-style-type: none"> * Form support groups * Do home visits
Surrogate	<ul style="list-style-type: none"> * Talk to problematic individuals at home.

The following findings emerged from the analysed data of the community nurses, clinic health managers and parents according to the specific roles of the community nurse:

4.4.1.1 The community nurse as a teacher

In response to why the community nurses should encourage other parents to bring children with disabilities to the clinics, the community nurses identified their teaching role:

*Yes, specifically to enlighten them [parents of children with disabilities] about the necessary conditions (QRS NU*DIST text: 31/77).*

The parents also identified the teaching role of the nurse, by indicating that the community nurse should influence the community to accept a child with a disability by raising awareness and giving health education on disabilities (see table 4.4, above).

(See QRS NU*DIST texts: 103/56-72 parents describing the role of the community nurse.)

4.4.1.2 The community nurse as a resource

From the data it was clear that the community nurse should be resourceful, to refer children with disabilities and their parents for further help. The community nurses described their role as a resource as follows:

*They are referred to genetics clinic at Mafikeng provincial hospital (QRS NU*DIST text: 31/59).*

*If a parent wants a child to attend school, like Witrand school in Potchefstroom, we refer to Social Worker (QRS NU*DIST text: 411/61).*

However, further analysis of data revealed constraints with the referral system from the clinics to the Provincial hospital. The community nurses raised concern on the referral system as follows:

*Our problems with referrals are since Mafikeng is a provincial hospital it is difficult to do follow-ups, even lose our client (QRS NU*DIST text: 411/74).*

*Not knowing whether she [patient] was helped or not. (QRS NU*DIST text: 411/74).*

The concerns raised by the community nurses over the referral system were confirmed by the clinic health managers. On interviewing the eight clinic managers on problems with regard to the referrals in the Mafikeng district, the following related issues emerged:

- ❖ Delay of ambulance or ambulance not available *(45%)
- ❖ Strained relationship between the district and the provincial hospital *(45%)
- ❖ No standardised referral criteria, resulting in complaints from the hospital *(80%)

❖ No feedback from the hospital *(90%)

(* percentage of clinic managers who identified the specific issue).

It also emerged from the data that there are community factors related to the problems with the referral system, namely:

- ❖ Resistance of the community to being referred to the provincial hospital.
- ❖ Community not satisfied with quality of care at the provincial hospital.
- ❖ Financial constraints of the community to travel to the provincial hospital.

The University of Pretoria (Do Disabled Children ... 2002:11) reported the financial constraints of the community to access a service, which revealed that due to poverty, parents could not pay for transport to access points of help like hospitals and social work offices.

In the current study, the referral system is viewed as crucial because children with disabilities and their parents need quality care that should be provided by other team members in the hospital. The concerns raised suggest that the referral system in the Mafikeng district health services should be reviewed and improved for the sake of all the patients, especially children with disabilities and their parents, who need psychosocial support to be integrated into the community.

The parents supported the role of the community nurse as a resource by stating positively that, as parents, they would encourage other parents of children with disabilities to visit the clinics to be referred when the need arose and to be helped to apply for disability grants (see table 4.4, page 86).

4.4.1.3 The community nurse as a counsellor

Counselling is a very important activity of the community nurse, and the goal of counselling is to assist the client and the family to accept the limitations of the disability and focus on the individual's strengths and abilities (Stanhope & Lancaster 2000:628).

The data analysis revealed that basic counselling was given as the need arose:

*Advising them to bring children for treatment... (QRS NU*DIST text: 32/58).*

The literature review raised concern over the low level of counselling services for persons with disabilities (7%) and counselling services for the parents/family of children with disabilities (1%) (South Africa 1999:157) (see table 2.1, page 27). These findings stressed the importance of the counselling role of the community nurse in assisting parents of children with disabilities to cope with the condition.

From the data analysis, it is clear that the parents support the importance of the counselling role, by indicating that counselling should be given by the community nurse to the parents of a child with a disability and the extended family (see table 4.4, page 86).

The community nurses identified the need to attend relevant training courses to improve their skills to manage children with disabilities in the clinics, and this would consequently improve their counselling skills on disability.

4.4.1.4 The community nurse as a leader

The leadership of the community nurse in addressing the barriers to integrating children with disabilities into the community, organizing awareness campaigns on disabilities, referring for further care and encouraging a team approach is discussed under section 4.4.5, page 114 (see figure 4.6, page 114).

By raising awareness on disability issues, the community nurse as a leader is identifying the need to change community attitudes to adults and children with disabilities, and enlighten others on this need (Stanhope & Lancaster 2000:629) (see chapter 2, section 2.3.4, page 28).

The data analysis revealed that the parents of children with disabilities in Mafikeng confirm the leadership role of the community nurse. The parents emphasised that the community nurse should

involve the communities and schools in addressing issues of disabilities (see *QRS NU*DIST texts:103/56-87* and table 4.4, page 86).

4.4.1.5 The community nurse as a technical expert

It emerged that as a technical expert, the community nurse identified the need to recommend sunscreen cream for children with albinism.

*Isn't it that children with albinism have a sensitive skin to sunrays due to lack of melanin, so we advise them on sunscreen cream to protect the skin (QRS NU*DIST text: 43/67).*

The technical expert role also emerged from the data noting the eagerness of the community nurses to do home visits to follow-up on children with disabilities. To support the nurses, the parents also stated the expectation that the community nurses should do home visits.

However, from the data it emerged that the community nurses are not doing home visits due to lack of transport and shortage of staff as discussed in detail in section 4.4.4 (pages 110 and 111). According to one of the community nurses:

*We want to do home visits, and we should be able to see how we can help families effectively and reach them, to see how they live, see the background of the family, now the main problem is transport, we can't reach them (QRS NU*DIST text: 632/136-138).*

In the technical expert role, the parents further identified that the community nurse should be instrumental in encouraging the formation of support groups.

4.4.1.6 *The community nurse as a surrogate*

As a surrogate, the community nurse assumes the advocacy role (Smith & Maurer 1995:17). This role was captured when the community nurse identified the need for a special service:

*... and that was not all, to claim a 3^d party, I helped them ... (QRS NU*DIST text: 631/147).*

4.4.1.7 *Overview of discussions*

The positive findings on the parents' perception in this study are contrary to Chubon (1982) and DeLoach and Greer (1981) (in Gething 1994:22), who found that the attitudes of health and rehabilitation professionals were negative, and could have a profound influence on the effectiveness of treatment and the self-esteem of the client with a disability. The impact of the community nurses' attitudes is discussed further in section 4.4.3 (page 94).

The data analysis of the parents' views on the roles of the community nurses are consistent with the findings of Stanhope and Lancaster (2000:628), Smith and Maurer (1995:16), Kromberg et al (1997:13), South Africa (1999:157) and Kerr and McIntosh (1998:229) that the role of the community nurse is viewed positively.

This study found that the role of the community nurse as a teacher, resource, counsellor, leader, technical expert and surrogate as described by the community nurses and parents was identified as important to address the barriers to the integration of children with disabilities (see section 4.4.5, page 114, for full discussion).

The specific role also determines the competence of the community nurse to integrate children with disabilities into the community.

4.4.2 Competence of the community nurse to integrate children with disabilities into the community

The following were some of the questions asked to the research participants to achieve this objective (see annexure C).

Questions to parents

Q: Has the community nurse been helpful when you brought your child with a disability to the clinic? In what way?

Tswana: *A go nale thuso e e maleba e o ntseng o e bona go mooki fa o tlisa ngwana wa gago yo o golafetseng mo kliniking?*

Q: Would you encourage other parents of children with disabilities to visit the clinic to get assistance from the community nurse? Why?

Tswana: *A o ka rotloetsa/gakolola batsadi ba bangwe go tlisa bana ba bona ba golafetseng mo kliniking go bonwa ke mooki? Naa mabaka.*

Questions to community nurses

Q: Would you encourage other parents of children with disabilities to visit the clinic? Please elaborate.

Q: How do you manage children with disabilities brought to the clinic?

The views on the competence of the community nurse to integrate children with disabilities were presented differently by both the community nurses and the parents. Data that emerged and were discussed in section 4.4.1 (page 85) also determined the competence of the community nurse to integrate children with disabilities.

The specific competence of the community nurse on disability issues could not be established from the data analysis. In a previous report discussed in chapter 2, parents doubted the competence of the community nurse. For example, the parents complained of poor assessment skills, prejudice and incompetence among professionals that led to the banishment of the children with disabilities and their families (DICAG Report 1998:18).

From table 4.1 and figure 4.1 (page 80), it is clear that the community nurses need training to be competent to manage common disability cases in the Mafikeng district. As indicated in table 4.1, out of the eight clinics, only two of the nurses attended a genetic course (one week).

The data analysis indicated further that the nurses also identified the need for relevant training and workshops to improve their skills on disability issues.

The need for appropriate training is consistent with the findings of Cole (1999:217) and Mitler (1995:108) cited by Davies and Green. In South Africa, the findings support those of Davies and Green (1998:97), Eloff 2001:16–17), Uys (2000:6–7) and Department of Health (2000:14–15).

The need for training and workshops emerged in the focus group discussions when the community nurses stated:

*My point is that there should be workshops for staff, I mean people at grass-roots level must be educated on disability. We should not only help those people according to a prescribed book, we must do these things practically (QRS NU*DIST text: 6411/226-277).*

*OK, people must workshop us on what they have learnt, especially with genetics, we are blank! (QRS NU*DIST text: 6411/231).*

The community nurses also felt that at the clinics, they were ignored and not considered for attending the relevant workshops [on disabilities], and preference was given to the officials in the offices. This view was expressed as follows at one of the focus group discussions:

*When these workshops are organised, they send people from offices who don't need that information as we need it in the clinics (QRS NU*DIST text: 6411/229).*

Relevant training on disability issues was identified as one of the main strategies to address barriers to the integration of children with disabilities (see figure 4.6, page 114).

4.4.3 The community nurses' attitudes and views on integrating children with disabilities into the community

The following were among the questions asked to the research participants to achieve this objective (see annexure C).

Questions to parents

Q: Has the community nurse been helpful when you brought your child with a disability to the clinic? In what way?

Tswana: *A go nale thuso e e maleba e o ntseng o e bona go mooki Fa o tlisa ngwana wa gago yo o golafetseng mo kliniking?*

Q: Would you encourage other parents of children with disabilities to visit the clinic to get assistance from the community nurse? Why?

Tswana: *A o ka rotloetsa/gakolola batsadi ba bangwe go tlisa bana ba bona ba golafetseng mo kliniking go bonwa ke mooki?*

Questions to community nurses

Q: What do you understand by integration or inclusion of children with disabilities in the community?

Q: Do you think that a child with a disability would benefit from being integrated into the community? Please elaborate.

The community nurses' attitudes to the integration of children with disabilities was determined by finding out their understanding of integration. The responses (data) were categorised into understanding integration in relation to education, family, community and the Department of Health (see figure 4.3 below and table 4.5, page 96).

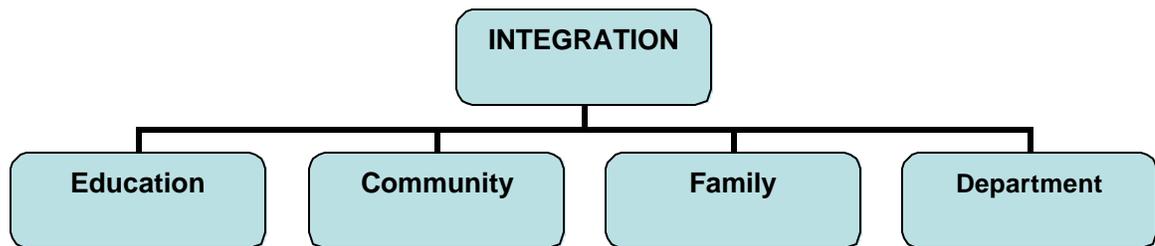


Figure 4.3

The community nurses' understanding of integration

The data analysis revealed that the community nurses were positive about the integration of children with disabilities into the community. The nurses viewed the integration process as a team effort of education, community, family and the Department of Health as illustrated in table 4.5, page 96.

Table 4.5 The community nurses' description of integration

Role of education	Included in normal schools School buildings to be adjusted
Role of community	* Accept as part of society - not discriminate - not isolate - not reject * Involve them in community activities - teaching or giving health education about their conditions - involve in sports - youth groups * Improve their sense of belonging * Their self esteem will be build * Don not look at them suspiciously
Role of family	* To understand condition of child * To be part of a caring team
Role of department	* Develop policy guidelines

Another way of determining the attitudes and views of the community nurses was to find out whether they thought that the children with disabilities would benefit from being integrated. The responses are represented in figure 4.4 (page 97). The parents' responses to how their children would benefit from being integrated into the community are also represented in the themes in figure 4.4.

Themes that emerged from the data were classified according to benefits to the family and the community.

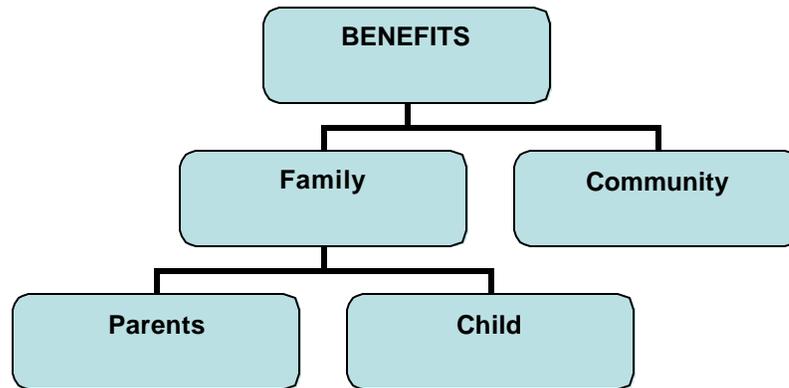


Figure 4.4

Benefits of integration of children with disabilities into the community

THEME 1: BENEFITS TO THE FAMILY

The findings on the theme of benefits to the family are discussed under (1) Benefits to the parents and (2) Benefits to the child with a disability.

❖ **Benefits to the parents**

The study established that if the child with a disability is integrated into the community, it would also benefit the parents because the parents would be encouraged not to hide the child with a disability. Furthermore, it emerged that the parents would receive the necessary support through counselling and other educational programmes. It was also highlighted that close family relatives would also be educated.

The benefits to the parents are supported by the community nurses' understanding on the role of the family in integrating the child with a disability into the community (see table 4.5, page 96).

The findings in this study support those of Beckman et al (1998:131) that the families who participated in the study to determine the importance of inclusion reported the importance of having a sense of community or feeling of connection with others.

❖ **Benefits to the child with a disability**

From the data analysis, it was clear that the person who would benefit most from the integration process is the child with a disability. It emerged that the child with a disability would benefit from being integrated into the community by becoming part of society.

The data analysis established that to facilitate the integration process, the child with a disability should participate in sports, give health education and lectures on disabilities, and should also participate in awareness campaigns.

It was also established that participating in all these activities would enhance the confidence of the child with a disability. The child with a disability would consequently:

- ❖ be able to face the public
- ❖ have a feeling of acceptance
- ❖ have a sense of belonging
- ❖ feel loved and needed
- ❖ know self help
- ❖ have a good self esteem
- ❖ have an improved morale
- ❖ have basic needs identified and met
- ❖ have potentials met
- ❖ have a decreased sense of shyness

(See *QRS NU*DIST texts:512/108, 109, 122 and 6412/101*).

The benefits to the child with a disability was also expressed as follows by one of the community nurses:

*... during disability awareness days, they [children with a disability] should be given a chance to talk so that they can know that they belong (QSR NU*DIST text: 512/110).*

The findings in this study that the child with a disability would be the one to benefit most from being integrated into the community confirm those of Johnson and Darrow (1997:174), Gherardini (2000:62), Double the Life (2002:3), and the UNICEF Report (1999:32) (see chapter 1, section 1.2.2.3, page 10 and chapter 2, section 2.6.1, page 33).

THEME 2: BENEFITS TO THE COMMUNITY

From the findings of this study, it is clear that when a child with a disability is integrated into the community, the community will benefit as well.

However, the study also found major factors in the communities that are barriers to the integration of children with disabilities in the community. The integration of a child with a disability therefore has important community benefits that should encourage a change of attitude in the community towards adults and children with disabilities. The data analysis indicated that if the child is part of the community the community would benefit positively as follows:

- ❖ The community's acceptance process will improve.
- ❖ It will help the community to exercise patience with different disabilities.
- ❖ The importance of special schools helping these children will be recognized.
- ❖ The community will notice the potential in the child with a disability.
- ❖ The community will realize that the child can be productive and contribute to the development of the community.

At a focus group discussion, one of the community nurses felt very strongly that the community would also benefit from integrating children with disabilities into the community as follows:

*... the community will see potential in the disabled child and that they can be productive (QSR NU*DIST text: 512/112).*

In Georgia, USA, Logan et al (1995:42) found that the presence of students with a disability in inclusive education sparked an understanding and acceptance of difference, and the non-disabled students developed empathy and compassion (see chapter 2, section 2.6.2, page 34).

It emerged from the findings in this section, that the community nurses are positive about the integration of children with disabilities into the community, despite the constraints identified in section 4.4.4, page 101-113.

In a study on inclusive education in KwaZulu-Natal, Rocher (1993) (cited in Davies & Green 1998:98) found that despite the many problems, there was an incredible dedication and optimism among the principals and teachers (see chapter 2, section 2.2.2.1, page 22).

The community nurses further identified benefits for the whole family as well as the community. In the researcher's view, the community nurses' positive approach will facilitate the process of integration.

However, Davies and Green (1998:98) warn about the positive approach and cite Weiner (1986) who maintains that practitioners' positive belief in inclusive education suggest that an individual's role influences what is called a "norm to be kind" to those with limitations. It is hoped therefore that in this study the community nurses' positive approach is genuine as they live in the community and share the same values as the parents.

In support of this study, Davies and Green (1998:97) further cite Baker and Gottlieb (1980), who believe that teachers' attitudes 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 (see chapter 2, section 2.6, page 32).

4.4.4 Barriers to the integration of children with disabilities into the community

The following were some of the questions asked to the research participants to achieve this objective (see annexure C).

Questions to parents

Q: What is the attitude of other members of the family towards your child with a disability? Explain.

Tswana: *Balosika ba tsa a jang ngwana wa gago yoo o nang le bogole? Thlalosa.*

Q: What are the factors that influence society to accept your child with a disability?

Tswana: *Fa o akanya, ke eng mabaka a a ka dirang gore batho ba o agileng le bone ba amogele ngwana wa gago yo o golafetseng mo setshabeng?*

Questions to community nurses

Q: What are the barriers to the integration of children with disabilities into the community? Please elaborate.

Three major barrier factors (themes) emerged from the data on the barriers to the integration of children with disabilities into the community: the (1) family, (2) community, and (3) health system (see figure 4.5, page 102).

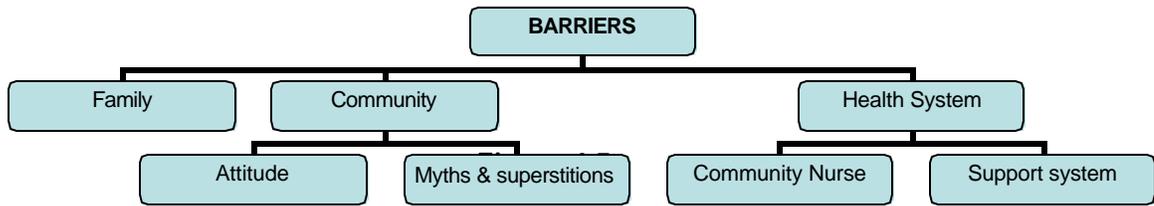


Figure 4.5

Barriers to integrate children with disabilities into the community

THEME 1: THE FAMILY AS A BARRIER

From the data analysis, it emerged that the community nurses identified the families as barriers to the integration of children with disabilities into the community. The community nurses maintained that the parents are barriers because of ignorance and a tendency to isolate or hide the child from the public. This observation was confirmed by the fact that the community nurses do not seem to see many children with disabilities in the clinics.

For example, the community nurses and clinic managers expressed the following sentiment in response to the disability cases seen at the clinics:

*Parents feel ashamed that other patients will be looking at the disabled child (QSR NU*DIST text: 21/53).*

*Parents should give us permission to reach out to the disabled child and allow nurses to help and take away the concept of "segole sa ka" (my disabled child in a protective manner) (QSR NU*DIST text: 632/142).*

At the same time, this observation of the parents hiding their children contradicts the parents who responded positively that they did not have problems with bringing their children with disabilities to the clinics (see section 4.4.1.1, page 86).

The parents did not see themselves as barriers to the integration of children with disabilities in the community. Even to the question of the attitude of other family members, most of the parents, except one mother, indicated that they got support from other family members:

*Oh no! They accept him well (QSR NU*DIST text: 5122/287).*

However, contributory factors have been reported that indicate that parents are ignorant and hide children with disabilities. For example, in Australia one of the barriers to the integration of people with disabilities into Australian life was the families' not knowing where to get relevant information (Evaluation of the Commonwealth Disability Strategy 1999:37) (see figure 2.1, page 21). The findings of a study by the University of Pretoria in 2002 in Orange Farm, South Africa support the Australian findings. The Orange Farm study revealed the following closely related findings of why parents may not come to the clinics:

Reasons for lack of access to education, rehabilitation and care dependency grants, given by the parents at Orange Farm (Do disabled children ... 2002:11):

- ❖ *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 e.g. pay for transport to access points of help like hospitals and social work offices.
- ❖ *Transport* . The special schools and rehabilitation services are outside 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* of the service providers towards persons with disabilities.

In addition to these factors, the community's attitude towards children with disabilities may contribute to the parents hiding the child. This concern was raised by most of the parents during the focus group discussions:

*Neighbours tell my child she is mad, therefore she no longer plays with their children, only stays at home (QSR NU*DIST text: 5122/290).*

*She is accepted well, sometimes not. You see she likes to attend church and the congregation complain she is restless and irritating (QSR NU*DIST text: 5122/285).*

THEME 2: THE COMMUNITY AS A BARRIER

The community emerged as an important barrier to the integration of children with disabilities into the community. The study confirms the findings of international and South African reports and studies on the negative attitudes of the community to adults and children with disabilities.

The theme, community as a barrier is categorised into (1) attitudes of the community, and (2) myths and superstitions.

❖ Attitudes of the community

The findings of this study revealed different opinions on the attitudes of the community towards children with disabilities. Some of the parents indicated that the attitude of the community to their child with a disability was satisfactory:

*Neighbours accept her and it boosts morale and self-esteem (QSR NU*DIST text: 5122/293).*

The data analysis revealed that the majority of parents were not impressed with the community's attitudes, which is in line with most of the findings of previous studies.

Children with disabilities are often unable to defend themselves and are undervalued by those around them, and thus become particularly vulnerable to emotional abuse (DICAG Report 1998:17).

In this study, the emotional abuse of children with disabilities emerged as a major concern. The parents complained that the community abused and ridiculed children with disabilities. For example, children with disabilities are sent around unnecessarily by neighbours to engage in abusive activities because they cannot defend themselves.

It was evident that the right of these children not to be emotionally abused is not recognised (see sections 9 (3) of the Constitution of South Africa, as well as the Convention on the Rights of the Child, as discussed in chapter 1, section 1.2.1.4, page 6).

According to some of the parents in the focus group discussions:

*Mine, they say she is stupid with a big head and mad (QSR NU*DIST text: 5122/282).*

*My neighbours say the child is stupid, she sent her to school of stupid children so that she can get money (QSR NU*DIST text: 5122/297).*

From the data analysis, it is clear that the people who felt the impact of the negative attitudes of the community were the parents and the children with disabilities themselves hence their withdrawal from the public.

The community nurses also supported the parents that the community's ignorance on disability was a barrier to the integration of adults and children with disabilities into the community.

These findings are consistent with those of Gething (1994:22) that the attitudes of the community towards persons with disabilities in Australia was a major barrier to the integration of persons with disabilities into the community (see chapter 1, section 1.2.1.2, page 3 and figure 2.1, page 21).

Gething (1994:22) found further that the negative attitudes to people with disabilities were associated with the perceived weakness of persons with disabilities. The current study established that the perceived weakness results in the emotional abuse of children with disabilities.

To further highlight the plight of children with disabilities and the families, this study found that there is also peer group pressure from other children, who make fun of children attending special schools. This, in turn, puts more pressure on the families:

*She is accepted but labelled by other children that she is attending mentally ill school and mad "setseno". I accommodate the remarks, because I think they are just children (QSR NU*DIST text: 5122/284).*

Another factor in the attitude of the community which emerged as interfering with the community nurses' service to provide quality care to children with disabilities and the families was the impatience of the community at the clinics. The community claim to be exercising their right not to wait too long for service at the clinic. According to one of the nurses:

*You know the very community puts pressure on us, they are harsh, then it is the community and the workload (QSR NU*DIST text: 631/148).*

The constitutional rights of children with disabilities are entrenched in the Bill of Rights of the Constitution of South Africa and Article 23 in the Convention on the Rights of the Child (see section 1.2.1.4, page 6). The child with a disability should therefore not be emotionally abused on the basis of disability and should be protected from degradation and exploitative labour practices.

❖ Myths and superstitions

From the data analysis, it was evident that myths and superstitions in the community are barriers to the integration of children with disabilities in the Mafikeng district.

As indicated in section 4.2.1 (page 79), the research participants comprised black nurses and parents, and were mostly Tswana speaking. It is assumed that there is a common belief in these myths and superstitions in the community of the semi-rural area of the Mafikeng district.

The impact of myths and superstitions on disabilities was highlighted in chapter 1 (section 1.2.1.2, page 4) and chapter 2 (section 2.2.1, page 20). The National Programme of Action (Children in 2001:113) indicates that myths and ignorance about a disability often result in the 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.

The following myths and superstitions emerged from the data:

- ❖ child with a disability is a family affair, and the society should not know about it (“segole sa ka” concept/ my child with a disability in a protective way)
- ❖ the child should be hidden from the rest of the community for fear of:
 - stigma – the family being rejected
 - other community member’s refusal/reluctance to marry into a family where there is a child with a disability.

The following remarks of the community nurses support the argument that myths and superstitions are barriers to the integration of children with disabilities into the community:

*Myths – if you accept disabled children, you’ll end up having a disabled child (QSR NU*DIST text: 62/152).*

*Culture. For example when in our household we believe the disabled is your "own" (ke segole sa ka), you should hide them, people should not know about them (QSR NU*DIST text: 62/153).*

*Once you have disabled a child, people will refuse their relatives to marry into that particular family (QSR NU*DIST text: 62/154).*

This study confirms Gething's (1994:22) finding that negative attitudes to 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.

THEME 3: THE HEALTH SYSTEM AS A BARRIER

From the data analysis, it is clear that the health system is a major challenge to integrating children with disabilities into the community. The health system as a barrier was identified mainly by the community nurses and clinic health managers. They indicated that the health system affects the entire quality of care to the patients, and consequently the quality of care to the child with a disability.

However, other aspects that are specifically a threat to quality care to children with disabilities will be discussed under the different themes. The health system as a theme is further categorised into (1) support system and (2) community nurses.

❖ Support system as a barrier

Five factors emerged from this theme, namely:

- ❖ Lack of support from the authorities

- ❖ Shortage of staff
- ❖ Lack of educational material on disabilities
- ❖ Non-availability of social workers
- ❖ Lack of transport.

Lack of support from the authorities

Lack of support from the Provincial and District authorities to the clinic staff emerged from the data analysis as one of the major barriers to providing quality care in the clinics. The community nurses complained that the Provincial and District authorities rarely visited the clinics to discuss specific problems.

There was a sense of frustration (evidenced in the quotes) from the community nurses that there are a lot of problems with general service delivery, and they are not given the necessary support by the relevant authorities.

In the focus group discussions, the community nurses expressed lack of support as follows:

*Lack of support from the senior authorities. Should they come to us or we should come to them? (QSR NU*DIST text: 632/221).*

*The Department must step down to interact with those at the lower level for the sake of the disabled children. We don't see them to raise our concerns (QSR NU*DIST text: 642/208-209).*

In previous studies lack of support from the authorities did not emerge clearly as a possible barrier. However, a related finding could be discerned in the results of the Evaluation of the Commonwealth Disability Strategy (1999:37) survey in Australia, which revealed a lack of awareness of the needs of people with disabilities. This could be argued on the basis that the authorities do not visit the clinics to

identify and discuss the specific needs of adults and children with disabilities in the respective clinic and communities with the community nurses.

Shortage of staff

Shortage of staff emerged as another major barrier to giving the child with a disability the necessary attention. This is clearly reflected in table 4.1 and figure 4.1 (page 80), which show gross shortage of nurses. The shortage of nurses was raised by the community nurses and clinic health managers.

The parents also observed the shortage of staff as a problem. They pointed out that the community nurses should do home visits, but due to the nurses' workload in the clinics, home visits were not done.

The shortage of nurses is a major challenge facing the nursing profession. According to the Sunday Times Business Report (African Nurses Blocked 2003:2), an international study on nursing found that it is a worldwide problem that should be addressed by the authorities (see annexure H).

The shortage of nurses could be closely related to studies on inclusive education where teachers complained of high numbers of pupils in classrooms as problematic to inclusive education.

Lack of educational material on disabilities

Lack of educational material on disabilities was also raised as a barrier. The community nurses indicated bureaucracy as a problem in getting the material from the districts:

*We don't have educational material on especially disabilities, and we have to go through a lot of channels of Assistant Director and District (QSR NU*DIST text: 6413/133).*

This lack is similar to Buysse et al's (1998:170) finding that inadequate classroom facilities were a barrier to inclusive education.

Non-availability of social workers

The research participants identified social workers as the closest health professionals to handle the issues of children with disabilities, because of the psychosocial implications of disabilities. However, the unavailability of social workers in other instances emerged as a threat to providing comprehensive care to children with disabilities and the families. According to the community nurses:

*Our problem is unavailability of social workers, we only see them after 3 or 6 months (QSR NU*DIST text: 643/172).*

Lack of transport

The community nurses identified their leadership role and remarked that there is a need to do home visits to follow up families of children with disabilities in the community. However, due to a lack of transport and shortage of staff, it is not possible to do the home visits:

*Transport is the main problem, because as community nurses, we want to do home visits, we should be able to see how we can help families effectively and reach them, to see how they live, see the background of the family, now we can't reach them! (QSR NU*DIST text: 632/137-138).*

❖ The community nurse as a barrier

According to some of the community nurses, the negative attitudes of the community nurses are sometimes a barrier to the integration of children with disabilities in the communities. One of the community nurses stated openly:

I think another barrier is our attitude as nurses towards the disabled children.

Sometimes they visit the clinic and our negative approach drives them away.

*We must be positive! (QSR NU*DIST text: 61/631/143-144).*

The nurses identified negative attitudes as possible repellents to the parents of children with disabilities, with the result that the parents do not bring the children to the clinic.

On probing the cause of the negative attitudes, the community nurses alluded to factors like:

- ❖ pressure of work
- ❖ lack of motivation due to unmanageable workload
- ❖ shortage of staff
- ❖ attack and attitude of the community being impatient to get the service
- ❖ work conditions of working day and night duty.

These findings support the DICAG Report (1998:18), which stated that parents of children with disabilities maintained that professional service providers were the direct cause of keeping children with disabilities in the "back room". The parents complained that the service providers' approach to parents and the negative attitudes did not empower the parents. This results in the parents' reluctance to take the children with disabilities to a health service in order to avoid humiliation (DICAG Report 1998:18).

According to Chubon (1982) and DeLoach and Greer (1981) (cited in Gething 1994:22), evidence suggests that attitudes of health and rehabilitation professionals are negative and can have profound influences on the effectiveness of treatment as well as on the self-esteem of the client with a disability. According to a study conducted in Orange Farm by the University of Pretoria (Do Disabled Children ... 2002:11), negative attitudes of service providers is a constraint for the child with a disability and the parents to access the necessary education and health services.

Despite the pressures, the community nurses' positive attitudes emerged from this study. The community nurses related instances which clearly confirmed the importance of positive attitudes of nurses. For example, one of the nurses related the following:

*To add to what Nkele said Neh!, attitude is important, because last year one child was involved in a car accident and the leg was amputated. So you know, the mother we gave her that warm welcome and the way we treated the child, after a year a prosthesis was provided, right now she is at school. That was not all, to claim the 3^d party I helped them, I even wrote a letter to insurances relating the condition after the accident, so now the mother came to thank us because the child got the money (QSR NU*DIST text: 631/147).*

These findings confirm those of Stoiber et al (1998:121) and Davies and Green (1998:100), who also cite Rocher (1993) in this regard, that the attitude of health professionals are positive despite the many problems encountered in inclusive settings.

The parents' responses indicate that they were satisfied with the care from the community nurses. The parents did not see community nurses as possible barriers to the integration of children with disabilities in the community, but rather had a positive regard for the nurses, and felt that the community nurses should be helpful in changing the attitudes of the communities to persons with disabilities (see section 4.4.1, page 85). The parents' positive response supports the findings of Davies and Green (1998:100) and Stoiber et al (1998:121).

Most of the findings that emerged from the data analysis on the health system as a barrier confirm Buysse et al (1998:170), citing Peck, Hayden and Richardson (1989), who identified the following barriers to integrating persons with disabilities into the community:

- ❖ problems in preparations for integration
- ❖ concerns about the adequacy of resources
- ❖ potential conflicts among various stakeholders.

4.4.5 Strategies to address the barriers to integrating children with disabilities into the community

The following were some of the questions asked to the research participants to achieve this objective (see annexure C):

Questions to parents

Q: How can the community nurse influence society to accept your child with a disability?

Tswana: *Fa o akanya, mooki wa mo kliniking a ka thusa jang gore ngwana wa gago yo o golafetseng a amogelwe senlthe ke baagisane kampo a amogelwe mo setshabeng?*

Questions to community nurses

Q: How would you address the barriers to integrating children with disabilities into mainstream society? Please elaborate.

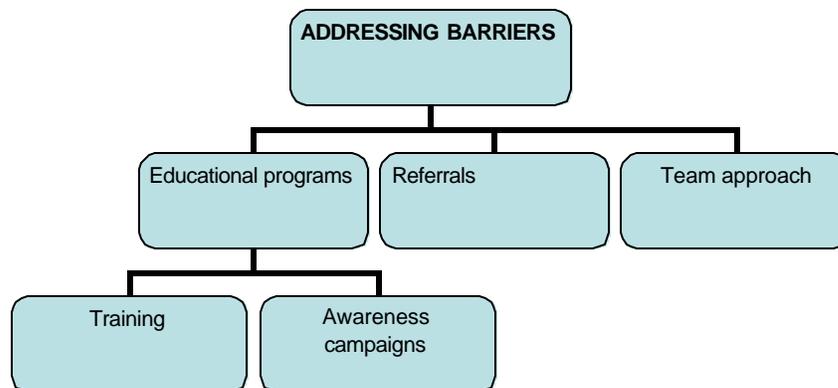


Figure 4.6

Strategies to address barriers to integrate children with disabilities into the community

The major strategies that emerged from the data analysis on addressing the barriers to integrating children with disabilities into the community were educational programmes, referrals and a team approach (see figure 4.6, page 114).

From the data analysis, it was clear that the role of the community nurse as a teacher, resource, counsellor, leader, technical expert and surrogate is important in dealing with and overcoming these barriers.

THEME 1: EDUCATIONAL PROGRAMMES

The theme on educational programmes is further categorised into Training and Awareness campaigns.

❖ Training

From the data analysis, it is clear that there is a need for the community nurses to attend training that will improve their skills to manage children with disabilities. It emerged that by attending the relevant training on disabilities, the community nurses' counselling skills would also improve.

It was also clear that most of the nurses interviewed had not attended any courses, such as genetic courses, to improve their competence to manage disability cases in the clinics. Table 4.1 indicates that from the eight clinics where data was collected, only two of the nurses had attended a genetic course (one-week course). The implications of appropriate training, with reference to previous studies, is discussed in detail in section 4.4.2, page 92.

This study established that a community nurse who is competent in disability issues will facilitate the integration of children with disabilities into the community.

❖ Awareness campaigns

This strategy highlights the role of the community nurse as a teacher to enlighten the community on disabilities. The role of the community nurse in co-ordinating awareness campaigns emerged as an important strategy to address the plight of the child with a disability and the family. Section 4.4.3 (page 98) clearly identified how the child with a disability would benefit from participating in awareness campaigns.

The research participants identified the need for the community nurse to use media and radio talk shows to raise awareness on disability issues. Giving talks in churches and health education to communities were seen as important. Accessing the relevant educational material, like pamphlets and videos, will enhance understanding of particular conditions.

However, lack of educational material on disabilities and the bureaucracy entailed in accessing material were identified as one of the barriers to addressing the needs of children with disabilities (see section 4.4.4 (page 110)).

The findings on educational programmes are consistent with the suggestions given by teachers to address the problems related to inclusive education (Davies & Green 1998:100):

- ❖ provision of remedial teachers
- ❖ specialist assistance for the teacher and child
- ❖ parental involvement
- ❖ teacher aides, teacher aid teams
- ❖ apparatus
- ❖ skills training

(See chapter 2, section 2.8.3, page 39-40 and figure 2.3, page 40).

THEME 2: REFERRALS

The role of the community nurse as a resource to refer the child with a disability and the parents for appropriate care emerged from the data analysis. It also emerged that the community should also refer cases to the clinics. The expectation was also expressed that mothers with genetic disorders should be given genetic counselling at the ante-natal clinic.

The role of the community nurse as a resource was discussed in detail in section 4.4.1.2 (page 87) with reference to the relevant literature.

THEME 3: TEAM APPROACH

From the data analysis, it was clear that there was a need for a team approach, a comprehensive team, and the formation of support groups.

Comprehensive team

The role of the community nurse as a leader emerged from the need to establish a comprehensive team. The leadership role of the community nurse also encompasses the surrogate role because, as a leader, the community nurse should be an advocate to identify other key role players of the team, and co-ordinate the services of the team.

It was suggested that the team should comprise the community nurses, social workers, teachers, Child Protection Unit, community, psychologists, District Head office and other professionals. The roles of each member of the team should be clearly defined and understood, and there should be collaboration with each other. The families were also identified part of a caring team (see figure 4.3, page 95). One of the nurses expressed the need for a comprehensive team as follows:

*We must all understand our roles, for example, if a teacher see a child with a learning disorder, she must be able to help ((QSR NU*DIST text: 643/171).*

However, the non-availability of social workers in other instances was raised as a concern by the community nurses (see under section 4.4.4, page 111). As indicated earlier, the social worker is regarded as the closest health professional to the community nurse to handle the psychosocial implications of disability in a family. The surrogate role of the community nurse should therefore be used in this regard to advocate the improvement of welfare services.

The University of Pretoria's study at Orange Farm (Do Disabled Children ... 2002:11) also found a lack of a team approach to services, with little evidence of active co-operation between the Health, Education and Social Development Departments, and the community-based organisations of persons with disabilities.

Support groups

The formation of support groups emerged from the data as a strategy to address the barrier problems. This is in view of the technical expert role of the community nurse as discussed in section 4.4.1.5 (page 90) According to one of the community nurses:

*Since we see them most of the time, we should encourage parents to form support groups, so that they can give each other moral support (QSR NU*DIST text: 6413/174).*

4.4.6 Overview of the discussions

The data analysis clearly supports the community nurse's role as a teacher, resource, counsellor, leader, technical expert and surrogate to deal with the barriers to integrating children with disabilities into the community.

This study found that, despite the related problems, the community nurses identified the benefits of integrating children with disabilities into the community and are determined to do so. This suggests very strongly that the community nurse needs support from the authorities to carry out these roles effectively and efficiently in order to improve the quality of life of children with disabilities and their parents.

However, the barriers related to the family, community and health system to integrating children with disabilities into the community are a major challenge for the community nurse. This makes it imperative therefore for further research on this topic as will be recommended in chapter 5.

4.5 CONCLUSION

This chapter described the data analysis, using codes and categories, with the aid of the QSR NUD* IST computer programme. The research findings were discussed with reference to the research problem, literature review and the research objectives.

Chapter 5 concludes the study, makes recommendations for improving the health care services for children with disabilities as well as for further research, and briefly discusses the limitations of the study.