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INVESTIGATING THE LIVES OF CHILDREN WITH DISABILITIES IN THE QWAQWA REGION: IMPLICATIONS FOR SERVICE PROVISION IN A RURAL CONTEXT

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ABSTRACT

This study investigated the factors that impact on the lives of rural children with disabilities and their families. Seventeen children with disabilities were selected through a process of purposive sampling from three areas in the Qwaqwa region: Mabolela, Makgalan and Bolata. This was a qualitative study. The research method was the semi-structured interview. The main caregiver in each of the families was interviewed. The findings in the study indicate that, despite the fact that various pieces of legislation and policy documents in South Africa since 1994 make special reference to the protection of the rights of children with disabilities, the rights of the children investigated in this study continue to be violated. The study reveals the urgent need to address barriers to learning and development that these children are experiencing; these barriers are located largely in the system. This study has implications for planning services to address the needs of children with disabilities in this rural context.

INTRODUCTION

Services for children with disabilities in South Africa have lagged far behind the estimated need. Historically, educational provision and support services for these children operated along racial lines with massive inequities evident in services available to black and white children, particularly African learners (Department of Education 1995). Currently the inadequacy in making provision for African learners with disabilities is extreme. Research carried out by the National Commission on Special Needs in Education and Training (NCSNET) and the National Committee on Education Support Services (NCESS) (Department of Education 1997) indicated that despite the introduction of compulsory education by the new government, many children with disabilities remain excluded from formal education. The most marginalised learners and the most discriminated against have been rural learners with disabilities and other special needs, such has those experiencing learning difficulties (Department of Education, 1997). As in other developing countries, the limited numbers of high-cost special schools serve a small minority of children with disabilities.

The development of educational provision and support services in the country has been defined by a strong adherence to a medical, deficit-orientated model of disability (Fulcher 1989; Peters 1993). This model led to negative attitudes, stigmatisation and the marginalisation of learners with disabilities. The White Paper on the National Disability Strategy (Office of the Deputy President 1997) criticises this model and argues that it undermines the rights of individuals with disabilities, and denies them status as productive and equal citizens in society. In most the provinces there has little attempt to address the fact that the education system is failing to meet the needs of the majority of learners with disabilities (Department of Education 1997). Learners with impairments in rural contexts are disabled by a system that has relegated them to the periphery of concern and has failed to provide for their needs.

The Report of the NCSNET and NCESS (Department of Education 1997) suggests that a major barrier to learning and development for learners with disabilities is negative attitudes in society. The Commission and Committee found that negative attitudes, lack of awareness and labeling result in the needs of children with disabilities not being met in the country. Discussions with parents revealed that the birth of a child with disabilities leads to ostracism from the community, and for women it can lead to ostracism from the immediate family. The finding was that this was reinforced in some communities by negative attitudes towards disability evident in some religious and traditional beliefs. The Commission and Committee found that teachers often respond negatively to the inclusion of a child with a disability in their classrooms, and that learners with disabilities are not valued in the school environment. A lack of awareness and inadequate training of teachers compound the problem.

As would be expected, there is a dearth of information or research on rural children with disabilities in South Africa. This study was an attempt to investigate how rural children with disabilities and their families in the Qwaqwa Region of the Free State experience their lives. The aim was to explore the following research questions:

- What are family and community perceptions of disability, and to what extent do these influence attitudes?
- What is the nature of educational provision and support services available in this rural context for children with disabilities and their families?
- How do social, economic and political factors impact on the lives of rural children with disabilities?

RESEARCH METHODOLOGY AND DESIGN

This study used a qualitative research methodology. The aim was to gain insight into qualitatively different ways in which people perceive, understand and experience the world around them. According to Sherman and Webb (1988) qualitative research is a methodology that allows this kind of investigation. They explain that qualitative research implies:

... a direct concern with experience as it is 'lived' or 'felt' or 'undergone' (p. 7).

In the study the lives of rural children with disabilities were explored from the perspective of the main caregiver. Semi-structured interviews were used as the method of data collection. Interviews were conducted in Sesotho and audiotaped. These were then transcribed and translated into English for the purpose of data analysis.

The first stage in the research process involved selection of the subjects. A form of purposive sampling was employed. It was decided to select children between ages 4-16 who had clear disabilities, for example, visual disabilities, physical disabilities, hearing impairment and intellectual disabilities. It was also decided to include both children who were in a formal school setting and children who currently have no access to schooling The study was conducted in three rural areas in Qwaqwa: Bolata, Makgalaneng and Mabolela. These areas were randomly selected from areas that were deemed "clearly rural" in that the communities were subsistence farmers and lived largely off the land.

The researcher worked with three ordinary schools in each of the areas in order to identify the target children. The selection of schools was done with the assistance of the Education

Department District Manager. All primary schools in the three areas were contacted and informed of the proposed study. However, only those schools that indicated an eagerness to participate in the study were included. Three target primary schools were then randomly selected from each of the three areas. As a result of this process the following were the total number of schools that participated in the study: Mabolela area – 3 schools; Makgalaneng area – 3 schools; and Bolata – 3 schools.

The aim was to work with pupils and teachers in order to find a pool of children in the communities who had clear disabilities. It was felt that the teachers and pupils would be the best resources to use since there was no official audit done nor data available on children with disabilities in the district. In order to locate "out of school" children with disabilities, it was decided to use the "child to child approach" discussed in Miles (1995). In the study by Miles (1995) conducted in Lesotho, school children were used as researchers in obtaining information on the children with disabilities in the community. To carry out this task, the researcher requested the teachers to ask their pupils to inform the school if they knew of any child with disabilities in the community. Data was forwarded to the researcher. In addition, all teachers at the schools were requested to provide the researcher with a list of children with disabilities in their classes. Only families who were prepared to participate in the study were selected.

Selection of Subjects

On the basis of the above process, 17 children were identified for participation in the study. Six were from the Mabolela area, 5 from the Makgalaneng area and 6 were from the Bolata area. Nine of the children were in formal school contexts. Many of these children were integrated into the schools on an informal basis in that attendance was irregular. The children's ages ranged from 6 years to 16 years. The 8 children who were in ordinary schools were located in classes ranging from Grade 2 to Grade 5. It was clear that their level of academic performance did not match the grades in which they were placed. It seemed that they were placed in the most appropriate social groupings, taking into account their chronological ages. One child was in a day care centre for children with disabilities run by a mother. Eight children were at home with no access to schooling. Six children were female and 11 were male.

Qualitative Data Analysis

Interviews were audiotaped and transcribed, and thereafter translated into English. Qualitative analysis of the data was carried out by both narrative reconstruction of the subject's accounts and experiences, and categorisation of personal accounts into themes that emerged.

RESULTS OF THE STUDY

The Family

The composition of the family unit differed in each of the 17 households. Thirteen were female-headed households. Three can be described as nuclear families, comprising both parents and children. In 6 families the grandmother's state welfare grant for the aged (R480.00 per month) was either the main source of income, or it contributed to the household income.

Perceptions about Disability

All 17 caregivers have a vague perception of the kind of problem the children are experiencing. None of the children was assessed in any formal way since birth, nor were parents given any insight into the nature of the disability. Some of the responses were:

- *"SP has a brain problem. Actually, he does not understand a thing, he just can't comprehend things. At school he is not learning anything. You know he is 14 years old but he is unable to learn. He is like a child in Sub A. He is a person who needs constant supervision because he also touches and handles hot water. He actually does not have an understanding to distinguish between dangerous things. You know, he still can't differentiate between morning and afternoon, he can't even tell what time it is". (Mrs MS)*
- *"He is not progressing at school. He is not learning anything. Personally I thought he was being naughty, but as time went I got reports that he is becoming uncontrollable.... he tears books and stuff and I was then called over to the school. He is not performing at all in school ... like I'm saying there is nothing that seem to be going into his brain. When he was still young I just took it for granted that, he is just a naughty child, who doesn't listen to what you tell him to do. (Mrs STBO)*
- *"He cannot be left alone ... he is all over the place... he climbs up the trees, rafters of abandoned houses. The other day he had to have stitches above the eye". (Mrs NM)*

Perceptions about the Child's Ability

The caregivers have made observations of the children's strengths and difficulties from their own day-to-day experiences with the children.

- *"I do not think he will be able to have a job – or even do some manual work. He can't even do gardening – even if he plays with his friends ... when they build toy cars with wire ... he is incapable of that." (Mrs MK)*
- *"From my observation, I realized that he is talented in using his hands, because some of the things he does with his hands are very appreciable and artistic. Yes, I see him working with ... maybe technical work or something" (Mrs ML)*
- *"I know he can do better at school if his eyes are healthy. He is able to tell what has been said at school. The problem is with written things because it is difficult to make out what is written. He complains that he can't see clearly on the board. He is not learning much." (Mrs HT)*

Attitudes towards Disability

All the caregivers expressed feelings of shock, guilt and disappointment when discovering that there was a problem with their children. They also indicated that there was nowhere they could have turned to for support at that stage. One mother described her experience in the following way:

- *"When I discovered that he has a disability ... to tell the truth I was in shock, you must understand my other children are fine. You know as an expectant mother, you expect a beautiful healthy baby, but when discovering that there is something wrong with them you are overwhelmed with a feeling of guilt and disappointment. You actually ask yourself questions like what went wrong - and you can't find the answer - that is what is most frustrating." (Mrs MK)*

Although teachers were generally supportive of parents, one of the mothers expressed her experience of lack of understanding and empathy for the child on the part of some teachers:

- *"You know with teachers, a teacher is something amazing. Even though I have been taking him to the doctor and submitting letters to the school ... it happens that sometime he meets another teacher who will handle him terribly because they don't have the time." (Mrs. STBO)*

Cultural perceptions of disability influence attitudes. The caregivers explained their experience of community attitudes as follows:

- *"I do not know the cause. It is just the way he is born, I think that the way he is naturally. People in the community have their own perceptions about everything - some attribute it to witchcraft - some think I have done something wrong, thus the child is with a disability." (Mrs MHT)*
- *"Some of the neighbours attribute his condition to sorcery. They say someone who hates my family did something to make him always faint so that he does not progress in life. They say because he is the only boy. I don't know what to believe, but as I said before I think that is the way he is naturally". (Mrs NM)*

Interaction with Professionals

Lack of information and lack of empathy on the part of professionals both at the time of being told about the disability and during ongoing contact are sources of dissatisfaction by parents. From the interviews, it is clear that the families obtain very little support from professionals, in particular, social workers and medical practitioners. No advice is provided on how to intervene with the children, or where families can access support. In most cases these professionals are located at the nearest hospital (a bus ride of about one and a half hours away). One of the caregivers has no idea where professionals who could help them are located.

The following responses indicate this:

- *"I even took him to Bethlehem (an hour and a half bus ride away) to see doctors. He said this child has a problem, and there is nothing they can do for him at the school because they are only teaching children who can learn. He said there is a problem in his head." (Mrs MHT)*
- *"I am aware of people called social workers, but I do not know what they do, and I do not know where to find them." (Mrs NM)*
- *"I don't know of any services where I can get help for my child." (Mrs MT)*

The response of one of the caregivers regarding her interaction with professionals reflected another dimension - power relations in the community.

It is clear that this particular caregiver feels that factors beyond her control are affecting her ability to access help from the Department of Welfare:

- *"Yes, I have been to the social workers for assistance - but there is one person who sabotages my attempt to seek help. The mother to these children is not taking care of them so I thought the social workers would help, but the man in charge was involved with my daughter at some stage. Now that they are not together any more, he is making things difficult for me. It is rather a long story, which I am not prepared to go into details." (Mrs HT)*

Current Educational Provision

Nine out of the 17 children are in ordinary primary schools. However, it is clear that the schools are unable to respond to the educational needs of these children. One of the children is 16 years old and in Grade 5. It is likely that he has good potential academically. Despite being over-age, and although there have been no attempts at curriculum adaptation, he has made progress. All the 9 children currently at primary schools are not making progress academically. A comment by one of the mother's was as follows:

- *"The nearest school is at least 10 minutes away ... a ten-minute walk. He is not getting good education ... It's because he is not getting any speech training at an ordinary school. If he were at a school where teaching will invest time in training him it would be better. I think the government should help with my child ... like it is doing with the other children." (Mrs ML)*

It is encouraging that some teachers at these schools requested the caregivers to admit the children to school rather than have the children remain at home with little stimulation. The schools seem to provide some support to families in this rural context.

- *"When I took him to school he still didn't have language. He could not talk. Teachers at the school nearby suggested that I take him to school so that he will be able to interact and learn from other children. Now his speech is clearer." (Mrs MS)*
- *"He is not at school at present - you see the problem is that he is not progressing, but sometimes he goes and some other times he just stays at home. At first, his teachers were not happy about him going to school when he wants to, but since they realised his problem they are a little understanding. But they tried everything; but they are unable to teach him; despite all their efforts he still does not understand things a person his age finds easy to comprehend." (Ms MM)*

One of the mothers, Mrs MK, has a child of 9 years old who is physically disabled. The child was initially at an ordinary school, and as he grew older the mother had difficulty carrying him to the school each day. He then remained at home until a group of mothers began a day care centre. The determination of these mothers to create services for children with disabilities was evident.

Family and Community Support

The caregivers indicated that there was support from the family – but this support was seen largely in terms of financial support towards meeting basic needs. Just one caregiver felt that the family and community were supportive of the child at a social level. Only two of the caregivers have contact with other mothers who have children with disabilities. On the issue of support, the comments were as follows:

- *"It is very difficult to cope ... you always have to keep an eye on him, but we are surviving. There is no school for this kind of child around here, but the doctor said he knows of some school some where. He then investigated the prices, and I found the fee to be too high for me. My family does support me ... yes, because they do give me money to help in taking him to the doctors. There are no other organisations that can help me in this community. I do not know of any other parents who have a child with a disability." (Mrs MT)*

- *"My family is supportive. The only family I have is my mother and my children, so of course, my mother supports me in every way possible. There is not any support you get from the community. I cope in taking care of my children's needs - through the mercy of God, we just live one day at a time. I do not know other parents who have children with disabilities. I am not aware of any around."* (Mrs LS)

Concerns for the Future

The overwhelming concern expressed by all the caregivers is what the future of the children will be in the event of death of the caregiver. The grandmother of one of the children stated:

- *"It is very difficult to manage financially because I am a pensioner; if whatever food I buy gets finished before the next pay day, then it means trouble. In short, I can say it is a struggle. What concerns me most is wondering what the future holds for him and also for the other children. Seeing that their mother left them with me and went to live somewhere with some one else. I am old now ..."* (Mrs HT – grandmother).

Other concerns expressed were that the children should one day have a job and independence, that more appropriate educational facilities need to be provided by the government, and money to meet basic needs.

- *"We need to eat, drink and we need clothes, that is all we need. If only he could go to a school where he would be taught and trained to cope with this world's pressures and demands - so that he can take care of himself."* (Mrs. HT).
- *"I am concerned of what is going happen to this child when I am gone. I am the only person she has in her life. My worry is who is going to take care of her, because I cannot imagine her getting married. Men are not interested in girls like her."* (Mrs MK)

DISCUSSION OF FINDINGS

The findings from data gathered in this study provided in-depth information on 17 children with disabilities and their families from the perspective of the main caregiver. The results highlight the various social, economic and political factors that impact on the lives of the children and their families. In this section an attempt will be made to explore in more depth the themes that have emerged in the context of literature on other developing countries that was reviewed.

Meeting the Basic Needs of Families

In the case of all the families, the main concern is financial – a struggle to meet basic needs. All the caregivers expressed their disillusionment over the fact that the present government has done nothing to alleviate the economic problems of rural people, and that there has been no attempt to provide facilities for rural children with disabilities. As the majority of households are female-headed, the income per family is an absolute minimum. It is clear that these children live in conditions of under-nourishment, which would impact negatively on the developmental outcomes of a child with disabilities. The Report of the NCSNET and the NCESS (Department of Education 1997) stresses the need to address socio-economic barriers to learning and development, for example, lack of access to basic services, and poverty and underdevelopment.

Community-based projects in developing countries are exploring a more holistic, integrated approach to service delivery (O'Toole 1995). Programmes to improve the lives of individuals with disabilities are implemented in the context of whole community development and involvement. According to O'Toole (1995), subjects focus on essential health awareness, literacy development and income generation for the community. The focus is also on health promotion in communities. The Report of NCSNET and NCESS (Department of Education 1997) suggests that the fundamental principle of this approach is the bringing together of the various sectors such as health, labour, transport, welfare, education and NGOs to address problems and promote development collaboratively.

Educational Provision and Rehabilitation Services

The findings in this study indicate that none of the 17 children and their families has access to appropriate education and rehabilitation services. Parents in the study believe that special schools are inaccessible to them because of the high school fees required. Although nine of the children are in ordinary schools and may be benefiting from interacting socially with other children, the curriculum is largely inaccessible to these children. On the positive side, it is commendable that teachers at the local schools are open to having children with disabilities in school. In some instances teachers have requested that the child be placed at the schools. However, the caregivers have indicated that the teachers do not have the skills to respond to the needs of the children. In South Africa, in order to meet the needs of rural children with disabilities and their families, there is an urgent need to find alternative models of service delivery to the current Western models that serve only a minority of children. Lessons can be learnt from some of the initiatives currently underway in certain developing countries such as Lesotho, India, Ghana and Guyana (Stubbs 1995; Chaudhury, Menon-Sen & Zinkin 1995; Ofori-Addo 1990; O'Toole 1995).

Community-Based Support to Families

The findings in this study revealed limited available support for the family within the community. Some of the expressed and observed needs of the families in this study were lack of finances to meet basic needs, lack of employment, poor health care, lack of access to appropriate education and early intervention programmes for their children with disabilities, limited emotional and social support from the community, and a lack of income-generating projects for families of children with disabilities.

One finding that emerged very clearly is that all the families, including the mother who runs a day care centre, lack knowledge and information on the nature of their children's disability. They have a very naïve understanding of the impairment and how to intervene with their children. Building on parents' knowledge about disability will lead to their empowerment and will impact on their ability to serve as advocates for their children and in the community. There is a need for community-based programmes to uplift the community and to build a network of support. Community-based rehabilitation (CBR) programmes in many developing countries (O'Toole 1995) work on transferring knowledge and skills about disabilities from professionals to people with disabilities, families and members of the community. For example, home programmes for children with disabilities are conducted by family members and supervised by trained community members. This leads to support networks within the community being built up over time.

The Report of the NCSNET and NCESS (Department of Education 1997) recommends the development of community-based support services. The Report suggests that specialist support personnel from health, welfare, education and other sectors be rationalised to the district level. De Carpenter (1994) suggests the following ways in which district support structures can assist in the development of local provision:

- Awareness raising and sensitivity to the needs of individuals with disabilities and their families;
- Empowerment of communities in their attempts to develop a voice and a power base from which they can begin to develop;
- Assistance to schools in curriculum development and in creating schools that are responsive to diversity;
- Training and development courses to empower teachers and community workers in skills and knowledge to provide support to children with disabilities and their families, such as early identification and intervention.

Teacher Education Programmes and Curriculum Access

It is imperative that the welcoming ethos in many rural schools that admit children with disabilities be further developed. The urgent need for in-service teacher development programmes to build the capacity of these schools to respond to diversity needs to be addressed. Innovations in countries such as India, Lesotho and Guyana that have similar contexts to South Africa are encouraging and provide examples of good practice (Balasundram 1995; Chaudhury, Menon-Sen & Zinkin 1995; Khatleli, Mariga, Phachaka & Stubbs 1995; O'Toole 1995). The philosophy underlying these initiatives is inclusion (UNESCO 1994). One of the important principles is that every child has unique characteristics, interests, abilities and needs, and therefore education systems should take into account and respond to the diversity in the learner population.

Societal Attitudes

In all cases, the children with disabilities are cared for in the family and within the community. However, the attitudes of the community are varied. Some caregivers indicated that the community was sympathetic and supportive. According to one caregiver, some people in the community tended to label the children with the Sesotho word, "sehole". This word is extremely harsh and derogatory and could be translated as meaning "imbecile". The cultural perceptions of many community members was that the disability was the result of sorcery and witchcraft.

Societal expectations of "normality" have profound implications for the development of personal identity and therefore put particular pressures on individuals with disability and their families. The quality of life is determined primarily by the attitudes of parents, the family and the community, and by the social and physical barriers the child and the family encounter. An important component of interventions in this context has to be awareness raising and social integration of the disabled in an attempt to change attitudes, sensitise communities to disability issues, and address myths that impact on how disability is constructed.

Employment and Independent Community Living

One of the concerns of a number of caregivers in the study was about the future of the children with disabilities, in particular concerns about employment possibilities and independent citizenship. Other concerns were about the safety of the child, the future of the girl child and about future care once the caregiver has died.

McConkey (1996) stresses that a child with disabilities needs to experience life as a valued member of a family, a community and society, and to feel that he or she belongs to a social group. McConkey describes projects undertaken by the Cheshire Foundation International in a number of developing countries such as Thailand, Sri Lanka, the Philippines and Malaysia. These projects aim at helping people with disabilities to become full participants in their community. The projects largely involve vocational and life skills training. They include a range of service models to prepare people with disabilities for a productive life in their communities. Life skills, with an emphasis on personal care, household skills and socio-academic skills such as handling money, and vocational training for supportive and competitive employment need to begin at an early age.

McConkey (1996) and McConkey and O'Toole (1995) review these service models and suggest some key components that need to be included in a training model that is community based.

Conclusions and Implications of the Study

The findings in this study have important implications for service provision for children with disabilities in a rural context. The various provincial departments, including health, welfare, education, need to form partnerships to address the service needs of rural children with disabilities and their families. Some of these needs are community-based support networks to give families social and psychological support; educational provision and rehabilitation care within local communities; support for children and families within the education, health and welfare systems; information about available services; and training programmes for employment and independent living.

This study is significant in that it provides information critical to the conceptualisation of framework priorities for children with disabilities and their families in a rural context. As Zinkin (1995) argues, the question to ask when planning service provision is, "Whose priorities?" Professionals and policy makers assume that their interventions are appropriate and that they know what the priorities are for children and their families. It is critical that interventions take as a starting point information on how these children and their families are experiencing their lives in their particular context.

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