

**ABLE VOICES ON INCLUSION/EXCLUSION
– A PEOPLE IN THEIR OWN WORDS**

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This article presents a study that examined the life experiences of ten disabled students enrolled in secondary school in a rural context in South Africa. The methodology used to understand their life experiences of schooling is the narrative. The student's authentic personal stories were used to explore their experiences. Through stories of the ten students we were able to learn from the motivations, contextual dynamics, and struggles that have made and make meanings in their lives. By communicating their stories, the students have enabled the researchers to connect with their anxieties, concerns, perceptions, experiences and challenges in their learning environment. What becomes evident in this study is the fact that the processes inclusion and exclusion are multiple and complex, and are enacted within wider social and political contexts. Furthermore, findings in this study support the arguments put forth by Edwards, Armstrong & Miller (2001) that inclusion is not the binary opposite of exclusion, and that inclusion will not overcome exclusion. Evidence of exclusion will always be found in practices of inclusion. The challenge is constantly to subject these notions and practices to interrogation and deconstruction within the micro-practices of an organisation such as the school and its community.

According to UNESCO (1995) it is estimated that more than 500 million persons with disabilities live around the world. Between 120 –150 million are children. The majority of children with disabilities live in developing countries and 80 % in poor rural areas. Helander (1993) adds that 85% of the world's children with disabilities are below the age

of 15. In addition to being extremely poor, many rural children with disabilities are exploited, abused, abandoned, neglected or deprived of their basic rights and liberty.

According to the Report of the National Commission on Special Needs in Education and Training (NCSNET) and the National Commission on Education Support Services (NCESS) (Department of Education, 1997) most African children in South Africa have been deprived of equal and appropriate education opportunities. During the apartheid era, support services that did exist functioned according to racial lines where there were distinct inequalities in provision to black and white students. The most marginalised and discriminated against have been African rural students with disabilities. Consequently current inadequacies in terms of provision for African children with disabilities are extreme. Despite the many changes that have occurred within the South African Education system since 1994, the education of students with disabilities continues to be a low priority in many Departments of Education in the country. There have been suggestions that many children with disabilities are *mainstreamed by default* (Department of Education, 1995). However, according to the Report of the NCSNET and NCESS (Department of Education, 1997), all research and site visits carried out by the commission and committee reflected a very low enrolment of students with disabilities in ordinary schools. It must be noted that rural schools are the most poorly resourced in the country (Department of Education, 1995) and it is unlikely that the needs of students with disabilities in such contexts are being satisfactorily met.

In July 2001, the Ministry of Education released Education White Paper 6 entitled, *Special Needs Education: Building an Inclusive Education and Training System* (Department of Education, 2001). This White Paper reflects a major paradigm shift in education policy from a dual special education and general education system towards the transformation of general education so that the system is responsive to the diverse learning needs of all learners. In other words, it recommends a shift in thinking about *special needs and support services* towards a commitment to the development of an inclusive education and training system. Inclusive education is defined as

- Acknowledging that all children and youth can learn and that all children and youth need support
- Enabling education structures, systems and learning methodologies to meet the needs of all children
- Acknowledging and respecting difference in children, whether due to age, gender, ethnicity, language, class, disability, HIV status, or other infectious diseases
- Broader than formal schooling, and acknowledges that learning occurs in the home, the community, and within formal and informal contexts.
- Changing attitudes, behaviour, teaching methods, curricula, and environment to meet the needs of all learners
- Maximising the participation of all learners in the culture and curriculum of educational institutions, and uncovering and minimising barriers to learning. (Department of Education, 2001:6-7).

The White Paper recommends a systemic approach to the transformation of the system, and proposes the notion of identifying and addressing *barriers to learning and development* (Department of Education 2001:7). Barriers are seen as those factors that

lead to the inability of the system to accommodate diversity, thereby, causing learning breakdown and preventing learners from gaining access to equitable educational provision. Key barriers in the South African context identified in Education White Paper 6 are: Negative attitudes to and stereotyping of difference; an inflexible curriculum; inappropriate languages or language of learning and teaching; inappropriate communication; inappropriate and unsafe built environment; inappropriate and inadequate support services; inadequate policies and legislation; the non-recognition and involvement of parents; inadequate and inappropriately trained education managers and educators. (Department of Education, 2001: 7).

An important proposal made in Education White Paper 8 relates to the need for changes in the general education system so that learners experiencing barriers to learning can be identified early and appropriate support provided. It explains that an inclusive education and training system needs to be organised so that it can provide various levels of support to learners and educators. The White Paper stresses that in South Africa historically the learners who are most vulnerable to exclusion and learning breakdown are learners with disabilities and impairments. For this reason many of the short term goals target learners with disabilities – a key one being the mobilisation of the approximately 280,000 disabled children and youth outside of the school system who have no access to education. Another important proposal is made around the need for the transformation of limited number of special schools and other specialised settings so that learners who experience mild to moderate disabilities can be accommodated within general education settings.

Against the background of White Paper 6, the study presented in this paper investigated the schooling experiences of students with disabilities in an ordinary school in a rural context. In essence, it analyses the interactional dynamics of inclusion. The aim was to get close to the subjective reality of the disabled students, and portray the complex and rich features of their experience and self-identity within a general education setting.

The Research Context

Ten students at a rural secondary schools in the province of KwaZulu-Natal participated in this study. The students were all African, both male and female, and ranged between 14 and 19years. Although English was not the first language of the students, they were very fluent and competent in expressing themselves. All ten respondents were physically disabled. The students completed their primary schooling at the special school that adjoins the secondary school.

In the study, disabled students stories were used as a lens of investigating reconstructing and understanding the challenges of their experiences in an ordinary secondary school in a rural context Unstructured interviews similar to the non-directive counselling approaches used by Rogers (1945) where the use of empathy and *non-possessive warmth* are predominant, were used in this study. As stories can amount to vast sums of data the researcher used a tape recorder, and responses were later transcribed for analysis. On day one, the researcher spent approximately 30-40 mins listening to the students relate their experiences of life in this rural setting. The students were encouraged to teach the researcher about themselves, their experiences with teachers and peers, and their progress in the learning environment. By asking the students to teach him about their experiences,

the researcher was encouraging a relaxed conversational approach. At the end of day one, the recorded interviews were transcribed.

On day two, focus group interviews were held. The purpose of the focus groups was merely to encourage discourse, and to confirm some of the common themes that emerged the day before. At the start of the session the researcher mentioned some of the common threads that had emerged from the narratives. As a group, the students began to agree, disagree and talk about experiences. During this session, the students began to enter into dialogue with one another relating their own experiences around the themes. Through discourse the students' also began to verify some of their peers experiences. A few of the students also began to add experiences to their original narratives. Several new themes arose from the students' discussion.

Reflections on the students' experience

The experiences of the students described here raise some salient issues of growing up disabled in a developing country. The discussion below focuses on barriers to learning and participation, the effectiveness of the school in meeting the students needs, cultural attitudes towards disability, social relationships, the student's future aspirations, and quality of life in general.

Social risks and the vulnerability of children

According to the Report of the National Commission on Special Needs in Education and Training (NCESS) and the National Committee on Education Support Services (NCESS) (Department of Education, 1997), many children in South Africa are placed at risk by conditions in the wider community where they are often exposed to physical violence. Biersteker & Robinson (2000) report that in 1996, The Child Protection Unit dealt with 35 838 cases of crimes against children. The stories of the learners in this study show how vulnerable they were to violence in their young lives.

KM: I was shot in my back I was in hospital for a long time. The bullet has not been removed from my spine. I was caught in cross fire.

BN: I become disabled in 1997 when I was shot in my chest. The bullet is still lodged in my spinal column, and as a result I don't have use of my legs and hips.

NP: My disability is as a consequence of my step- father's aggression. He shot me when I was 7 when I was in Grade 5. The bullet was lodged in my spine. And that has affected the movement of both my legs.

Being included

Since 1994, a number of innovative initiatives, largely driven by non-governmental organisations, have emerged throughout the country in an attempt to meet the educational needs of children with disabilities (NCSNET & NCESS, 1997). However, many problems beset such initiatives towards innovative practices often relating to a lack of sustained resources, and inadequate support for teacher development and whole school development. The initiative at including learners with disability described in this study is one such innovation begun as a partnership between the two schools. In general, the students were positive about their inclusion in an ordinary secondary school. They

alluded to the fact that most teachers and peers were supportive and encouraging, and that the school was trying to address their needs despite limited resources.

BN: I enjoy schooling at this school because I find that the teachers respect me. I do not feel that I am treated different from other learners at the school by teachers. I know that teachers at special school do come here to speak to the teachers about learners with disabilities

LH: The teachers to try to teach each learner although we have large classes. It is difficult for them but they do try and help us with our difficulties. If I do not understand anything in class I feel quite comfortable to tell my teachers. All my teachers take the time to explain again – not only to me but to all other learners.

KM: I am presently in grade 10. I like everything about this school – the teachers, the other students and even the uniforms. The teachers are very encouraging and supportive. They encourage us to participate in all aspects of the school.

HN: Both my parents do not work, and as a result I am unable to pay my school fees. My principal says that I must not worry about the school fees. He is trying to help me to apply for a disability grant.

Barriers to access

One of the most significant barriers to learning remains the inability of students to access the educational provision that does exist and their inability to access other services which contribute to the learning process. Six of the ten students in this study experienced great difficulty in arriving at school on time. This was by no fault of their own. A major barrier was transport to and from school.

BN: When we travel by taxi. The people in the taxi say that we are wasting their time and that we are causing a delay. They also say that the wheel chair is taking up another passenger space.

LH: I wake up 5h30 to get ready. I leave home at 6h30. It takes me 45 minutes to get to school.

NP: If we travel by taxi it is with great difficulty. The taxis always give us a problem. They just pass me. They say that we are taking up their time.

HN: As there is no direct transport from my home to school, I have to walk for approximately 1½ hours to the taxi stop. The taxi drops me off on the main road and then I have a further ½ km to walk on the gravel to school. Sometimes when the taxis are in a hurry, they don't stop because they say I am slowing them down. I am often late especially in winter, as it gets very cold.

The students were anxious and concerned about arriving at school late, and when they discussed issues they would change in their learning environment many answered that there was a need for the school as an organisation to be more responsive to their particular needs.

HN: If I was the principal of the school, I will change the starting time to 8h00 as this will give us more time to get to school.

LH: If I were the principal I will change the starting time to 8h00.

Transport facilities are not easily available to the students, and when they are available, the passengers and taxi drivers are not keen to stop for them. The taxis and buses are also

physically inaccessible. They see the disabled students as wasting their time. They see the wheelchair as taking the space of an extra passenger. The students are perceived as a burden and an added cost. One student also felt disadvantaged when it came to school trips and excursions.

BM: When the school goes on excursions, I am unable to go on the excursions because the wheelchairs cannot get onto the bus.

Inadequate transport has been clearly articulated by the students with disability as a key barrier to accessing education.

A curriculum for all?

Although many students stories reflected positive experiences of the curriculum offered at the school, there was evidence of barriers embedded in the curriculum that were not being engaged with. From TM's comment it is evident that the school is extending the curriculum to include social issues that students' experience in their everyday lives.

TM: I love drama and Mr Mkize and Ms Magubane got me involved with an group, Drama in Aides Education (DramAide). The play I am involved in is about sexual abuse. I play a social worker who helps a abused child. I love drama and I wish we could study it as a subject at our school.

However, there are aspects of the schools' curriculum policy and practices that are exclusionary. For example, many of the students involved in this study had to make frequent visits to hospital. The students are often absent because of lengthy hospitalisation and regular medical treatment. When the students are hospitalised, no provision exists for learning support to continue during the period of treatment.

NP: Presently I have a problem with my bladder, and I have to go to the hospital often to change the catheter. I often have accidents because of the catheter.

HN: The doctors have conducted many tests and are trying to see how they can help. I would have finished school but because of my disability I often have to go to the hospital. As a result I miss the work and when I get back from hospital, I have to repeat the year.

Consequently many of the students like NP and HN have to repeat a year when they return from hospital. All the students interviewed in this study have repeated a year at least twice.

Even though The South African Schools Act of 1996 ensures that education is a fundamental right, which extends equally to all students, assessment processes must be re- evaluated. Assessment processes in a setting such as this particular secondary school are often inflexible. The seriousness of such barriers is obvious as many of the students with disabilities have been forced to repeat aspects of the curriculum, and as a result the age gap between disabled students who have repeated and other students was significant. Participation for all in sporting activities at the school is obviously a problem. On each Wednesday the school closes at 13h00 to allow sporting activities to take place. The students with disabilities are not able to access this aspect of the curriculum:

TM: What I don't like about my school is the difficult sports that the students play. I feel scared to play with the other students because they are rough, and they don't realise that I am using crutches. I used to play table tennis and I enjoy it because it is not rough. On a Wednesday school closes at 1h00 for sport. But the disabled students just watch the other students play. . It is difficult to play with the other students because we are not able

to jump and compete with the other students. I can compete in table tennis, javelin or shot-put.

BN: When I was at the special school, we did sport every week. I do not play sport or participate in any activities at the secondary school. It is difficult to compete with students who are able. I feel very restricted and short in my wheel chair. When I was at the special school, I did play table tennis and netball.

JM: I attended primary school at the special school. I used to love playing soccer but I don't play anymore

BL: I also enjoy music and love playing the marimbas. I played marimbas with a group of disabled students at the special school. I don't play it anymore because we do not have marimbas at the high school.

Although there are sporting activities for the non-disabled students, the disabled students are expected to fill the passive roles of spectators. When the researcher spoke to the teachers about why the students did not participate in sport, they responded that the students may get hurt. While the students with disabilities did feel intimidated about participating with the non-disabled students, many of them were also accomplished in a number of other sporting codes. A number of the students had played and excelled in table tennis, basketball, netball, soccer and athletics. The lack of provision for students to participate in sport with the non-disabled students not only impacts the learning process but also prevents the very needed social interaction.

However, one of the students reported his experience of sport at the school, which indicates the school is engaging with the issue of curriculum access.

MM: I enjoy sport. My favourite is athletics. This year I went to Cape Town for the disabled athletics meeting. I won three gold medals, and a trophy for javelin and discus. My school principal and teachers were very proud of my experience.

Cultural attitudes towards disability

Many of the students were aware that the other students at school and the people in the community perceived them as *not normal*. Cultural perceptions of many of the students in the school and community are that disability is the result of sorcery and witchcraft.

SM: The people say that the tokoloshe is inside me and that is why I cannot stand up. Many people including the school students say that I am ukuthathwa (bewitched).

MM: Some of them say that we are ngithakathiwe (bewitched) and ukukhubuzeka (disabled).

TM: I wish that the people in the community would just be more accepting of us so that our parents will be not shy or embarrassed with us.

Research undertaken by the National Commission on Special Needs in Education and Training (NCESS) and the National Committee on Education Support Services (NCESS) showed that negative attitudes towards disability are rife among both parents, educators and students. Discussion with parents showed that the birth of a disabled child often means ostracism from their immediate family as well. Such problems are reinforced by negative attitudes towards disability which are articulated in some religious teachings and traditional beliefs (Department of Education, 1997: 28)

Kisanji (1995) explains that in Tanzania the birth of a child with an impairment (or becoming impaired later in life) is viewed with suspicion, as this may be due to the wrongs committed by the parents or grandparents against God, the gods or the ancestral spirits. Negative attitudes towards differences and the consequent discrimination and prejudice as seen in SM and MM's context can also manifest itself as barriers to learning and participation.

Social relationships

While all the students involved in this study affirmed that the non-disabled students were tolerant, accepting and supportive, name calling, labelling and teasing in an unkind way featured regularly.

MM: The only problem I have at the school is with the Grade eights who come to our school from the primary school for the first time. When I pass them they talk amongst themselves and laugh. They call me names. When I confront them they say they did not say anything. When I turn to leave they laugh and call me names like Skhebe (little boat that rocks from side to side) ukukhubuzeka (disabled). Some of them say that I am ukuthakatha (bewitched). The students that are responsible for this behaviour are mainly the younger boys in grade 8.

MM: If had to change anything at the school will get the teachers to talk to the grade 7's in the primary schools so that they will not tease us when they arrive at the secondary school. They must be told about disability so that when they come to this school they will not stare and call us names.

QD: The grade 8's are not very friendly but the older students are friendly. The grade eights stare at the disabled students, and they make comments about us to each other. I think they do this because they do not know us. Some of them think that we should not be at the same school as them.

NP: I am in grade 8 but I don't play with any of the other grade 8's.

Five of the ten participants in this study felt that the Grade 8 students were guilty of bullying behaviour. They found that they teased, laughed at and name called the students with disabilities. This can be attributed to the fact that while the students in the school (Grade 9 –12) have been socialised to understand and respect diversity. It is clear that the new students to the school (Grade 8's) entered with the prevailing community prejudices and discriminatory views of disability. However, when the Grade 8's did get to know the students with disabilities the name calling and teasing did stop. As MM explains:

MM: However when they get to know me they are comfortable with me and are accepting.

The stories of students in the study suggest another perception: that the non -disabled students use the student's disability as a filter to assess their intelligence, character, beauty, personality and sexuality.

BN: Sometimes the other students are cruel and say things that upset the disabled students. I don't have a boyfriend because the guys say that I am only half a woman.

TM: I think it is because she has a boyfriend, and she thinks that because I am disabled, I will not be able to have a boyfriend. I now don't have any friends. The other girls think

that because I am disabled I will have nothing in common with them. This makes me sad. During break I stay in the classroom.

In TN and BN's situation the assumption is that if you are disabled then you are also sexually dysfunctional. According to the students with disability, the other non-disabled students perceive them as not interested in members of the other sex or incapable of engaging in sexual relationships. The non-disabled students have very set conceptions of what a sexually attractive person should look like. It is evident that deeply rooted beliefs about health, beauty and sexuality perpetuated by the media and society combine to create an environment that is often hostile to those whose physical abilities fall outside the scope of what is defined as socially acceptable.

Six of the students in this study were recipients of a state disability grant. Two of the students were conscious of the fact that the non-disabled students were aware that they were receiving financial assistance. They felt that the social relationships initiated by the non-disabled students were merely to exploit them for financial gain.

NP: The friends I do have are all disabled because the other students are aware that we collect a disability grant. I feel the abled students only use us for our money. When our money is finished then they don't associate with us. They always borrow money from the disabled students, and never pay us back. They also know when we collect our grants and then they will want to associate with us.

Some of the students did mention that they have had many positive experiences that made them feel welcome socially at the school, and that have formed friendships.

BL: I have a girl friend at the school. We are going out for eight months. If I have a personal problem, I speak to my friends about it. Other learners sometimes go to the teachers about their problems.

QD: I enjoy everything at this school. The children do not tease me. Every morning I wake up at 5h30. I have a friend who pushes me on my wheelchair to school. It takes about 30 mins.

BN: I enjoy being at this school. The teachers and most of the learners are very kind to me. I have two friends in grade 11.

Internalised oppression

From discussions with the students a marked theme emerged: internalised oppression. Hardiman & Jackson (1994) describes internalised oppression as so overpowering because it shapes the way people targeted with ablest oppression, think about themselves and others living with disability. Through the hurts from being treated as inferior, denied basic material needs, denied a fair share of resources, and demeaned, people with disability internalise or start to believe the things people say about them.

BN: I get scared because most of the disabled are unemployed and uneducated. All the disabled people I know have stopped school and don't work. They say that there is no work for disabled people because we are slow. Sometimes the disabled people make beads and bangles but they don't get enough money. I am concerned whether the university is made for disabled students.

BN in this example has started to internalise that people with disabilities are school drop-outs, and that there is no place in the society for her and persons like her. In this way students like NP with impairments are disabled by the social, political, and economic

barriers constructed by society. It is the barriers that are disabling rather than individual impairment.

Making a difference in a rural context?

In this study, students and researchers have been able to talk about what inclusion and exclusion mean to them in the context of a school that has opened its doors to learners with disability. In embarking on this initiative, it is evident that the school took a bold step in making a difference, that is, providing access to secondary education for a group of learners with disability. Through the use of stories, the researchers have been able to gain some insight into the students' experiences of schooling and life in the community.

The findings in this study raise certain critical issues. Firstly, a lesson to be learned is that there is a need to move away from over-simplistic notions of inclusion. Institutional access alone or a change of site does not automatically result in that learners being included. The notion of inclusion requires ongoing and rigorous analysis of the context into which learners are included. As Slee (2001) points out if this does not occur inclusive education becomes nothing more than a *default vocabulary for assimilation* (Slee, 2001:114).

Secondly, inclusive education cannot occur without introducing fundamental transformation to the system. This study reaffirms the critical need for a systemic approach to inclusion, and the need to continually probe issues of curriculum, assessment, pedagogy, and social relations in schools and communities.

Thirdly, the findings in the study suggest that social equality in the form of equal access to general education provision does not guarantee equity. Inclusive education initiatives that do not engage with relations of power and issues of equity can undermine the goal of social justice and democratic participation. On the positive side, inclusion can promote an awareness of difference and social exclusion, and an ongoing engagement of the complexities inherent in policies and practices.

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