

THE REALIZATION OF THE RIGHTS TO HEALTH,  
EDUCATION AND SOCIAL WELFARE AMONG  
DISABLED YOUTH IN INGWAVUMA AND  
BHAMBANANA, KWAZULU NATAL

Ali Mumford  
Advised by Dr. Steve Reid  
School for International Training  
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This study is dedicated to Sbongile, whose life ended too soon, but whose legacy is living in the hearts and minds of those who battle everyday to make proper healthcare a reality for all children in South Africa.

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## Abstract

This practicum based study was completed in an effort to explore the realization of the rights to health, education and social welfare for disabled children in Ingwavuma and Bhambana, KwaZulu Natal. Very little research has been done on disabled children in South Africa, and estimations of prevalence range from 3.3-6.4%.<sup>1</sup> The absence of accurate data creates a situation where implementation of policy and delivery of services is slow and does not always address the most urgent needs. The new South Africa aimed to bring rights and freedom to all groups of people, but the question which this study attempts to answer is whether or not disabled children living in this new era are at a greater advantage than they have been in the past. It is evident that since apartheid ended, “there has been significant progress in South Africa in terms of the development of policies to protect the rights of children with disabilities”<sup>2</sup>. This study identifies some of the gaps that still exist between these policies and their implementation.

Data was obtained through participant observation at Mosvold Hospital Therapy Department and Sisizakele Special School. In addition to direct observation, informal conversations with staff and students were also used as a means to collect primary data. These conversations provided a wide range of perspectives on how the children’s rights were being protected or not. Data was collected over a period of three and half weeks, in which half of the time was spent at each institution. Government policies and other secondary sources are used to compare what is envisioned on paper to what is being implemented at the study sites.

The study found that there remains a lot of work to be done in improving service delivery to disabled children at the study sites. The right to education is being realized by only one special school in the entire district, as there are yet to be any local mainstream schools willing to accept the students. Access to health care was found to be much better than access to education, but consistency of rehabilitative care remained a challenge for most children. Issues surrounding the misuse of the care dependency grant are also raised and analyzed in the study.

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<sup>1</sup> Landsdown, Garrison. Disabled Children in South Africa: Progress in Implementing the Convention on the Rights of a Child. 2002

<sup>2</sup> Service Delivery to Children Living with Disabilities. Children First Issue 55 2004. Christina Nomdo and Lerato Kegamphe.

## Introduction

The legacy of apartheid left disabled children in South Africa with an enormous burden of inequality and social exclusion.<sup>3</sup> Disability is broadly defined by, “social and physical environments and disabling barriers that prevent equal opportunities”.<sup>4</sup> Many of the barriers created by apartheid have yet to be resolved by the government and disabled children in the new South Africa face many of the same challenges as those in the past. The lack of information regarding disabled children is a major barrier to the “monitoring and protection of their rights”<sup>5</sup>, and has been a prime factor in the slow progress of policy implementation. Without a comprehensive understanding of the burden of disability it is difficult to plan for proper service delivery.

A study done in the rural Manguzi District of KwaZulu Natal in 2002 found the prevalence of disability in children under 10 to be 6%.<sup>6</sup> This is slightly higher than the 5% overall prevalence rate found in KwaZulu Natal in 2001.<sup>7</sup> Although prevalence statistics are ambiguous, it is evident that the burden of disability is far greater in rural areas and that children in rural areas have a much higher chance of having multiple impairments.<sup>8</sup>

In order to observe the experiences of some of the most disadvantaged and at risk disabled children, the rural towns of Ingwavuma and Bhambanana were chosen as the study sites. They are located in Northern KwaZulu Natal, in one of the most deprived districts in the province.<sup>9</sup> The study was carried out at two organizations, Sisizakele Special School and Mosvold Hospital Therapy Department. These locations were chosen because they aim to deliver two of the most basic rights; health and education. Through participant observation, the researcher sees first hand how those rights are being realized or not for the population of disabled children accessing their services. These institutions are also both directly and indirectly involved with the right to social welfare, which is also addressed in this study. The area has a very large burden of disability, with more than five hundred disabled children in the Mosvold hospital

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<sup>3</sup> Landsdown. Pg. 5

<sup>4</sup> Nomdo et al.

<sup>5</sup> Nomdo et al.

<sup>6</sup> Couper, J. Prevalence of Childhood Disability in Rural KwaZulu Natal. South Africa Medical Journal 2002. Issue 92.

<sup>7</sup> Statistics South Africa. Census 2001.

<sup>8</sup> Landsdown. Pg. 6

<sup>9</sup> Health Systems Trust. District Health Barometer. 2001

service area.<sup>10</sup> This setting was thus a prime location to investigate the gaps that exist between the policies which aim to protect the rights of disabled children and their implementation.

Although departments and systems in South Africa have yet to establish a consistent definition of disability, it is important to define the term as it will be used in this study. This paper adopts the definition used by the Department of Health, which states that disability is, “a moderate to severe limitation in a persons ability to perform daily life activities as a result of physical, sensory, communication, intellectual or mental impairment”.<sup>11</sup>

This paper presents the findings from the study sites and an analysis, based on the findings, of their ability to deliver services to disabled children. It offers an inside look, via participant observation, at how the programs operate and highlights their strengths and weaknesses. This information is then triangulated with a range of policy documents that define the rights of disabled children in South Africa. Through this analysis, the discrepancies that exist between policy and reality in relation to the rights to health, education and social welfare are emphasized . Policy documents used include the South African Constitution of 1996, the United Nations Convention on the Rights of a Child, and the new Children’s Bill. This analysis represents the situation of only one group of disabled children, but through the conclusions drawn from the study, it stresses the importance of protecting and supporting all disabled children in South Africa.

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<sup>10</sup> DART Situational Analysis of Disability. Chapter 3: Jozini Sub District Findings. 2002

<sup>11</sup> Philpott, S. “Vulnerability of Children with Disabilities”. South African Health Review 2006. Pg. 273

## **Methodologies**

The primary data for this study was gathered using participant observation and informal conversations with informants at the study sites. Participant observation took place at Sisizakele Special School in Bhambanana, KwaZulu Natal and at the Mosvold Hospital Therapy Department in Ingwavuma, KwaZulu Natal. A period of three and a half weeks was spent participating in the daily activities of the two organizations and observations were made about how they were run and how they delivered services to disabled children in the area. This approach offered a look at the behind the scenes work done at the organizations and not just the end result. During the participatory period, conversations were held with the staff and members of the organizations in order to get a broad range of perspectives and ideas about how the programs were run and how they benefited disabled children in the area. Informants included staff members of each institution, children at Sisizakele, a volunteer mother at Sisizakele, and mothers of disabled children in the therapy department. Each of the informants gave oral consent for their responses and information to be used in this study. In the case of child informants, the teachers consent was given in addition to the children's consent in order to ensure the protection of their rights. Ethics approval for the study was given by the SIT ethics review board.

Secondary sources were also compiled in order to compare the ideal rights and protections of disabled children as expressed in policy and legislative documents to their lived experiences at the study sites. An effort was made to use the most up to date and local research about childhood disability, although a number of the documents sited are national policy. The national policy documents were analyzed as they applied to the sites being studied and the analysis cannot be considered representative of the situation in other districts or provinces.

There are important limitations to the study that must be noted in order to place the findings in the proper context. The study was most restricted by the short amount of time spent at the study sites. Although it was possible to gain a good general picture of how the organizations operate and serve the disabled youth in the area, the period of time spent at each location was not sufficient to fully understand and analyze individual programs or all of the issues that were raised. Working with two organizations meant that only half the stated study period was spent at each, and this affected the amount of primary data that could be gathered from each source. The study is also affected and limited by the inexperience of the researcher. No previous course work on issues of disability in South Africa had been completed, and therefore the background



knowledge of the study topic was not comprehensive. This affected what kinds of questions the researcher asked of its informants, as well as how the information was processed and analyzed.

The short time of the study period also played a role in limiting the primary sources to those working at the study sites. Sources involved in policy creation and implementation were not included in this study. As a result, the findings in this study are biased to the opinions of the informants used. There are certainly perspectives from others involved in the process of policy implementation that may further complicate the issues raised.

## **Definitions of Acronyms**

ANC: African National Congress

CRC: Convention on the Rights of a Child

DART: Disability Awareness Research Team

DPSA: Disabled People South Africa

INDS: Integrated National Disability Strategy

PHC: Primary Health Care

UN: United Nations

## Background

### The Disability Rights Movement in South Africa

The disability rights movement in South Africa unofficially began in 1984 with the creation of the Disabled People South Africa (DPSA) group.<sup>12</sup> It was started by a group of disabled people, both white and black, who decided that something needed to be done about the discrimination against them by the apartheid government, and their inability to act on their own behalf. They were involuntarily tied to a health and welfare system that made them dependent on others.<sup>13</sup> It is important to recognize that although the black disabled population was already facing extreme poverty, violence and discrimination which were only multiplied by their disability, the white disabled population also faced a number of barriers that kept them from accessing basic health and welfare services. Therefore, the disability rights movement became a struggle against apartheid, but also against the ways that people viewed the disabled as dependent and helpless.<sup>14</sup> Maria Rantho, a past chairperson of DPSA describes the thinking which shaped the formation of the group in this way:

We felt that there was a need to create a voice of our own, where we would, for the first time, be able to advocate for our own rights, without having to depend on professionals to speak on our behalf...We felt that there was a need for such an organisation to be formed...because we know that disabled persons are deemed perpetually dependent on other to do things for them.<sup>15</sup>

This way of thinking motivated disabled people to make a difference in their own lives. DPSA continuously grew through the late 1980's and by the 1990's they were able to hold a small full time staff that was began working with the ANC to encourage integrated disability policies into the national legislation.<sup>16</sup> Their first major statement was made with the creation of the Disability Rights Charter of South Africa in 1992, which was formulated with the help of an international human rights law group. This was followed by a massive march by disabled people on the streets

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<sup>12</sup>Disability and Social Change: A South African Agenda. Pg. 47 Human Sciences Research Council 2006

<sup>13</sup>Disability and Social Change: A South African Agenda. Pg. 48

<sup>14</sup>Disability and Social Change: A South African Agenda. Pg. 48

<sup>15</sup>Disability and Social Change: A South African Agenda. Pg. 51

<sup>16</sup>Disability and Social Change: A South African Agenda. Pg. 56

in Durban, which resulted in a “total collapse of Durban’s traffic system”<sup>17</sup>. This protest put DPISA and the disabled community on the national map.

After small victories were won through rights granted to disabled people by the new Constitution, the momentum of the movement continued to grow. Today, there are a number of governmental policies and legislation that, on paper, protect and defend disabled persons from discrimination and exclusion. The most important of these is the Integrated National Disability Strategy, which was published by the Office on the Status of Disabled Persons (OSDP) in 1997.<sup>18</sup> In the papers foreword, Thabo Mbeki writes, “our government wishes to express its unswerving commitment to the upliftment and improvement of the conditions of those members of our society who are disabled”.<sup>19</sup> This strong language promises many things to disabled people, some which have been realized and others which remain promises. Today the movement continues to fight for self representation, economic freedom, and a move from the medical model of disability to social, human rights focused model.<sup>20</sup> One of the issues which has largely been ignored, that even the INDS fails to address (except for identifying them as a vulnerable group), is the needs and protection of disabled children. This study focuses on the struggle to have their rights realized.

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<sup>17</sup> disAbility. Issue Number 5, 1992.

<sup>18</sup>Disability and Social Change: A South African Agenda. Pg. 67

<sup>19</sup> Integrated National Disability Strategy White Paper. Office of the Deputy President. November 1997

<sup>20</sup> Disability and Social Change: A South African Agenda. Pg 69

## Mosvold Therapy Department

### *Location*

This district hospital is located in Ingwavuma, KwaZulu Natal in District 27, Umkhanyakhude. The 2001 census found this district to be the fourth most deprived district in the province, with less than 45% of the residents having access to piped water.<sup>21</sup> Some improvements were made between 2001 and 2005 and the per capita Primary Health Care (PHC) Expenditure increased by almost R150, one of the largest increases by any district.<sup>22</sup> Although this was a positive change, there is still an inadequate amount of this expenditure being spent on preventative health care. Mosvold hospital remains the epicenter of health for the district, with over fifty percent of PHC expenditure being put towards its operations which serves a population of approximately 110,000.<sup>23</sup> The deprivation of the district also manifests itself through the prevalence of HIV/AIDS in the district. In 2004, 56% of deaths in the hospital were due to AIDS.<sup>24</sup> The virus has essentially wiped out the working age population in the area, resulting in over 50% of the population being under twenty years old.<sup>25</sup> Essentially, all of the health issues in the district are compounded by the extreme poverty that the majority of the residents live in.

### *Staff and Services*

The Therapy Department was established in 1989 when the hospital was upgraded and renovated.<sup>26</sup> Today it is staffed by four physiotherapists, one occupational therapist, one speech therapist and two community rehabilitation facilitators. Three of the eight posts are currently taken by therapists completing their community service requirement. The department is headed by Sonja Higham, a physiotherapist who has been at the hospital since 2002. At the hospital, the department has a number of monthly support groups and clinics that use a group rehabilitation approach. Patients are assigned to groups based on their disability and level of function. The goal is to teach patients and their caregiver's appropriate exercises for their condition, so that they can do the rehabilitation on a regular basis at home. In addition to the work done at the hospital site, the therapists are responsible for serving 10 residential clinics on a monthly basis. The

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<sup>21</sup> Health Systems Trust. District Health Barometer. Deprivation 2001.

<sup>22</sup> Health Systems Trust. District Health Barometer. Health Expenditure 2005.

<sup>23</sup> Health Systems Trust. District Health Barometer. Health Expenditure 2005.

<sup>24</sup> KwaZulu Natal Department of Health. [www.kznhealth.gov.za/mosvoldhospital.htm](http://www.kznhealth.gov.za/mosvoldhospital.htm)

<sup>25</sup> DART Situational Analysis of Disability. Jozini Sub District Findings. 2002. Although this statistic is slightly dated, it is the most current data that could be found which referred specifically to the study area.

<sup>26</sup> DART Situational Analysis. Mosvold Hospital Findings 2002

department also assists patients in applying for disability and care dependency grants and provides assistive devices when they are available. As part of a public hospital the department is funded solely by the South African Department of Health.

### *Mission Statement*

The department operates under the following mission statement: “Striving together with people with disabilities, their families and the community to improve quality of life and for the development of rehabilitation.”<sup>27</sup> This study focuses on how the department realizes that mission statement through their work with disabled children in the hospitals service area

### *Challenges*

The challenges of the department are deeply rooted in a lack of communication between organizations and government departments. Sonja Higham, department manager, suggests that the problem is rooted in the fact that “there are a lot of groups doing a little bit for the patients, but there is no communication between the systems”.<sup>28</sup> The Departments of Health, Social Welfare and Education all operate independently and little regard is given to the policies of the other departments. The therapy department should be working closely with each of these offices, but without discourse between them, it is very difficult to provide comprehensive treatment that effectively pushes patients to realize their highest potential.

Another major challenge the department faces in relation to children with disabilities is awarding the care dependency grants. In some cases it is quite obvious that the child qualifies for the grant. Unfortunately, the majority of cases seen are not clear cut and the department struggles to make the decision of whether or not they qualify. Higham describes these cases as the “in-between kids”, and suggests that because the department of social welfare has a very poor and unclear definition of disability, the task of awarding grants is very difficult.<sup>29</sup>

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<sup>27</sup> As posted in the Mosvold Therapy Department on November 13, 2007

<sup>28</sup> Sonja Higham. Mosvold Therapy Department. November 20, 2007. 10:45 am

<sup>29</sup> Sonja Higham. Mosvold Therapy Department. November 20, 2007. 10:45 am

## Sisizakele Special School

### *Location and Demographics of Learners*

Sisizakele is a special school located in Bhambanana, KwaZulu Natal. It is within the Zululand Obonjeni School District. Bhambanana is small town and consists of a petrol station, taxi rank, and two small grocery stores. It is approximately 23km from Ingwavuma, the nearest town with government services and offices. The school currently serves a population of forty students from a number of communities in the district, most of which are hours away. The long distances are a consequence of Sisizakele being the only special school serving the entire district. As a result, all of the students board at the school and only return home on holiday.

The learning capacity of the students varies widely across age and severity of disability. The school caters to a number of different disabilities, the most common being cerebral palsy and spina bifida.<sup>30</sup> Some of the children attending the school are only physically or mentally disabled, while others have multiple impairments. The students are assessed upon admission and placed into grade levels one through four based on their developmental age and academic capacity. All of the current students' families are receiving the care dependency grant, part of which is meant to go towards the R300 a month school fee for boarding.

### *History*

Sisizakele (translated, we have found help) was founded in October 2002 by a group of therapists from four of the district hospitals in the Umkhanyakude district. In 1997, the therapists and parents of disabled children in the area began discussing the need for a school that catered to the needs of the disabled youth. In 2002, a situational analysis including child disability was done in the area by the Disability Research Action Team (DART). The study found an immense need for a school that would offer these children an education.<sup>31</sup> There were 870 children in the district who were identified as being unable to access education because of their disability.<sup>32</sup> These findings were taken to the Department of Education but they got no response. Determined to provide a learning environment for some of these children, in October 2002 the school was opened using volunteer teachers and a portion of the grant money from the fourteen students who

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<sup>30</sup> Physiotherapy Manual. Sisizakele School. 2007

<sup>31</sup> DART Situational Analysis of Disability. Jozini Sub District Findings. 2002

<sup>32</sup> DART Situational Analysis of Disability. Jozini Sub District Findings. 2002

were admitted when it opened. For two years the school operated in this way with no support from the government. The school rented out buildings at the Bhambanana training center, which were used as classrooms by day and cooking and sleeping quarters at night. It was not until 2004 that a response from the Department of Education finally came and official teaching posts at Sisizakele were made.<sup>33</sup>

In October 2007, the school moved to a new location about two kilometers down the road. They now have separate kitchen and sleeping facilities, as well as 4 classrooms, a reception area, a playground, a garden and two bathrooms. Unfortunately, Sisizakele is the only place for disabled kids in the whole district to attend school and although it does its best to accommodate the burden of disability in the area, it does not have the capacity to make education a reality for all those who seek it.

### *Staff*

Currently, the staff consists of three level one educators, four teaching assistants and a principal. None of the teachers have done specific course work in special education. There are also seven house mothers who live with the students at the school and handle all of their cooking and washing needs. These mothers are volunteers and receive a monthly stipend paid by the school. The majority of these women are the mothers of students attending the school. The school is also visited by therapists from the 5 hospitals in the district. A range of therapists come on a once monthly basis in an effort to reach each child at least once a month. The school is currently requesting posts for another teacher and a permanent therapist.<sup>34</sup> The creation of these posts will greatly benefit the school.

### *Vision*

The school does not have an explicit mission statement, but it does operate with a number of visions that act as its driving force. These include the following:

- To promote the best interest of the school and strive to ensure its development through the provision of high quality education for learners with mental and physical disabilities.
- To implement appropriate strategies to meet the needs of the children.

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<sup>33</sup> Sisizakele Special School Profile, as compiled by principle Ms. Jood. 2007

<sup>34</sup> Information from Lorato Jood. Sisizakele Special School. November 16, 2007. 8:45 am



- To educate the community about the needs and rights of children with disabilities.
- To link resources and man power from a variety of sources to benefit the children.
- To foster sound relationships amongst stake holders.<sup>35</sup>

These visions are slowly being realized as the school matures. As much progress as the school has made in the last five years, there is still a lot of hard work to be done before all of these visions become realities.

### *Challenges*

A major challenge facing the school right now is staffing. The Department of Education only has two teaching posts and a principal post available for the school. Three people are not capable of making a school run properly, especially when all of the students require special attention. The school is forced to hire additional teachers and assistants out of its budget which is intended to go to the educational programs. In addition to the lack of teaching posts, the department also offers no funding for the hostel program. The sheer distance away the children are from their homes makes it impossible for them to commute, so instead they are forced to pay a 300 rand per month school fee. When families are unable to pay this, the schools budget is again responsible for covering the costs. These burdens put on the schools budget greatly minimize potential for investing in educational programs and specialized equipment to make learning more accessible to the students.<sup>36</sup>

Another challenge the school faces is employing an appropriate curriculum. The teachers are currently using the same curriculum as the main stream schools and adapting it as they see fit. There are thus no real benchmarks that can be assessed. It would be very useful to have a curriculum that was prepared for learners with special needs so that it could be followed more closely, instead of the trial and error approach to the mainstream curriculum.

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<sup>35</sup> Sisizakele Special School Profile, as compiled by principle Ms. Jood. 2007

<sup>36</sup> Information from Lorato Jood. Sisizakele Special School. November 16, 2007. 8:45 am

## **Findings and Analysis: The Realization of the Rights to Health, Education and Social Welfare**

### **The Right to Health**

Child health has been made a global priority, most recently driven by the fight to realize the Millennium Development Goals by 2015.<sup>37</sup> Aiming to express their own commitment, “South Africa has adopted almost all international treaties, initiatives and programmes”.<sup>38</sup> This commitment has not yet proven enough to undermine the barriers to health experienced by all children and, “it is clear from the evidence presented that child health in South Africa is declining rather than improving”.<sup>39</sup> Not all health indicators are declining, but this quote refers to the overall status of child health. For disabled children, the current status of child health is compounded by poor access and social exclusion.<sup>40</sup> South Africa has adopted and created a number of policies within the last decade that aim to protect a child’s right to adequate health care, but their effects have yet to reach the most vulnerable children.

Ratified by South Africa in 1995, the UN Convention on the Rights of a Child addresses the right to health for disabled children from two angles. Article 23 states that, “State parties recognize the right of disabled children to special care...and ensure that the disabled child has access to and receives health care services, [and] rehabilitation”.<sup>41</sup> The article also stipulates that when possible, these services be provided free of charge. Article 24 goes on to say, “Parties recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health”.<sup>42</sup> These articles put the onus on the state to both provide and ensure reception of health care services.

The Constitution of 1996 also protects a child’s right to health in the Bill of Rights, although this document does not explicitly cite the health of disabled children. The plan to implement these rights was expressed in the National Program of Action for Children, which was created as an “instrument by which these commitments to children are being carried out”.<sup>43</sup> The success of the state in delivering the proper health to disabled children through the Mosvold

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<sup>37</sup> Shung King, M, Mhlanga, E, de Pinho, H. “The Context of Maternal and Child Health”. South African Health Review 2006. Pg. 108

<sup>38</sup> Shung King et al. Pg. 107

<sup>39</sup> Shung King et al. Pg. 124.

<sup>40</sup> Lansdown. Page 5

<sup>41</sup> Convention on the Rights of the Child. 12 Dec. 1989. Article 23

<sup>42</sup> Convention on the Rights of the Child. 12 Dec. 1989. Article 24

<sup>43</sup> National Program of Action for Children. 31 May 1996. Data used is from the introduction of the document.

Hospital Therapy Department is analyzed in the following section, which highlights the strengths and weaknesses as observed during the study period.

### Strengths of the Mosvold Therapy Department

Based on observations and information gathered, it was found that the system currently in place to identify and diagnose children at risk for disability is well run and followed up within the department. All high risk births are automatically registered with the therapy department, and in extremely high risk cases a therapist will attend the birth.<sup>44</sup> After birth the child is put into therapy's care and their development is checked at two, four, six and twelve months to determine if there are any delays.<sup>45</sup> If the child has reached typical developmental milestones by one year, they will be discharged from the department, but if a disability is diagnosed the child will be put into a rehabilitation group. The department has once monthly groups for babies, toddlers, and three cerebral palsy groups (mild, moderate, severe). Each group is run by members of the therapy team and is attended by mothers and their children.

The group approach is used as a way to try and educate caregivers so that they can provide care for their disabled child on a daily basis. During the study period, one of each therapy group was observed. It was found that the mothers varied greatly in their willingness to learn and apply the material, but those who were paying close attention seemed to benefit greatly. In the baby group one mother expressed her satisfaction with the group saying, "I learned how to interact with my baby and have other children interact with him".<sup>46</sup> Further, a volunteer mother at Sisizakele said that while her child attended the therapy group at Mosvold she was very happy because, "He learned to count while he was there, and he learned how to eat and drink".<sup>47</sup> This kind of satisfaction was consistently expressed by mothers attending the groups and reflects the success of the department. Through increasing the mothers' confidence in their ability to care for their disabled child, interaction between the two increased and consequently the child's health was improved.

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<sup>44</sup> Information from conversation with Sonja Higham, held while driving to home visits. November 8, 2007.

<sup>45</sup> Information from conversation with Sonja Higham, held while driving to home visits. November 8, 2007.

<sup>46</sup> Information from conversation between mothers and therapists at baby group. Mosvold Hospital Therapy Department. November 28, 2007. 11:00am

<sup>47</sup> Volunteer mother at Sisizakele Special School. November 26, 2007. 1:30 pm

The department was also found to have a strong commitment to accessing the care dependency grant for those that qualify. Essentially, the therapists fill out an application for every child registered with their department who is eligible.<sup>48</sup> The majority of the time the process is very challenging for the therapists because, “It’s very difficult to assess the in-between kids”.<sup>49</sup> There is not a clear and consistent definition of disability used by the Welfare department to determine who qualifies for the grant, making it very hard to determine whether or not some kids are eligible. Recognizing that the grant is a major determinant in whether or not mothers attend the therapy groups, the department worked diligently to access these grants so that they can provide rehabilitation to the maximum number of children.<sup>50</sup> Further, this commitment to social welfare ensures that the children are economically able to access rehabilitative care, just as the CRC suggests should be true.<sup>51</sup>

Throughout the study period the staff was repeatedly spending time doing work for their patients that other government departments (welfare and education) failed to complete. This includes grant applications and school assessments. They are not technically responsible for these processed but because it affects the well being of their patients, they put in the extra time. This dedication to delivering services positively impacts the lives of all of their patients.

## Weaknesses

The way the therapy groups were run was found to be affective for most mothers attending, but there were also mothers who were obviously not absorbing the information and interaction with their children was minimal.<sup>52</sup> In reflecting on the challenges faced by the baby group one therapist responded, “I didn’t like it when the mothers are just sitting and daydreaming while the group is happening, and not interacting with their child”.<sup>53</sup> Even though they spent the time and money to attend the group, some mothers seemed to grasp very little of the information and as a result the progress and health of their child was compromised. It was very evident within the groups which children had been worked with and which had not been. One physiotherapist expressed their frustration with the issue saying, “The worst is when mothers

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<sup>48</sup> Information from Occupational Therapist at Mosvold Hospital. Therapy Department. November 13, 2007.

<sup>49</sup> Sonja Higham. Mosvold Therapy Department. November 20, 2007. 10:00am

<sup>50</sup> Information from Occupational Therapist at Mosvold Hospital. Therapy Department. November 6, 2007.

<sup>51</sup> Convention on the Rights of a Child. Article 23

<sup>52</sup> Based on observations of therapy group on November 6, 2007. Mosvold Hospital

<sup>53</sup> Information from conversation between mothers and therapists at baby group. Mosvold Hospital Therapy Department. November 28, 2007. 11:00am

don't work with their children at home and I can see they aren't progressing".<sup>54</sup> The children's health was largely dependent on their mothers ability and willingness to interact with and challenge the child.

One issue observed that contributed to the lack of interaction among some mothers, was that at times the groups seemed unorganized. There were goals stated most of the time, but there often seemed to be a disconnect between what the therapist was trying to convey and the mother's understanding of concept.<sup>55</sup> It was vital for the mothers to have a clear understanding of how to take the activity and work with it at home, but in some cases this did not seem to be accomplished by the end of the group.

Another issue that arose was the poor communication between parties involved in the children's care. Therapist manager Sonja Higham expressed, "We struggle quite a bit with communication".<sup>56</sup> She went on to discuss the fact that there are a lot of different groups doing little bits for the kids but there is usually no understanding between groups about the care being given.<sup>57</sup> Groups included in the children's care are the departments of health, welfare and education as well as PGES, the psychological service which is supposed to be responsible for schools placements. The lack of communication often ends up resulting in the therapy staff taking time away from their primary responsibilities to do school assessments and deal with social welfare issues.

#### Analysis: The Realization of the Right to Health

The challenge of getting all of the mothers to follow through with the rehabilitative care at home could be addressed through approaching the therapy groups with more explicit goals set out for the mothers. It might be effective to create some form of chart with the most important exercises and activities listed and a recommendation on how often they should be done. That way the mothers could keep a record of the work they did with their child at home. A short period of time at the beginning of each group could be devoted to checking in with each mother and noting her progress. The mothers would have a greater sense of responsibility if they knew their progress was going to be checked. This kind of record keeping may also improve the work

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<sup>54</sup> Information from conversation between mothers and therapists at baby group. Mosvold Hospital Therapy Department. November 28, 2007. 11:00am

<sup>55</sup> Based on therapy group observation November 6 and November 13,2007

<sup>56</sup> Sonja Higham. Mosvold Therapy Department. November 20, 2007. 10:00am

<sup>57</sup> Information from Sonja Higham. Mosvold Therapy Department. November 20, 2007. 10:45am

the therapists are able to do with the children during the group, because they would have a more comprehensive understanding of what work had already been done. The mothers would also develop a sense of accomplishment by seeing the progress their child was making as a result of their efforts. A mother who is confident in her ability to teach and interact with her child can make a huge impact in their life, especially if they are unable to attend formal schooling. For disabled children in such a rural setting, it is imperative for rehabilitation to occur at home in order for progress to be made. The department should make it a priority to equip the care givers with as many resources as possible in order to increase the chances that proper care will be given in the home.

An easy way to undermine the success of a multifaceted program is to cut the lines of communication between participants. The right to health cannot be realized exclusively through medical means. If the highest attainable standard of health is to be realized, as the CRC suggests, “it is important for personnel within the health sector to develop a holistic understanding of the determinants of childhood disability”.<sup>58</sup> To be physically and mentally healthy, a disabled child needs not only rehabilitative care but also a sense of belonging within their society. This is realized through their familial and peer relations and how they come to view their self worth within these groups. Health can thus not be attained without cooperation among stakeholders. This issue is reflected in the idea that, “disability is a cross cutting issue. The lack of coordination and communication among programs within government departments and between government and civil society remains a critical factor undermining the prioritization of disability needs”.<sup>59</sup> The lack of communication between the therapy department, PGES, and social welfare is preventing the disabled children in the district from obtaining the standard of health they are entitled to according to the CRC and the Constitution. The government needs to mediate communication between the offices that contribute to and protect child health in order for the right to be realized.

### The Devastating Effect of Poor Communication

The story of one particular child illustrates the importance of a health system that makes communication a priority. The details of this case were provided by the Principle and a teacher

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<sup>58</sup> Philpott, S. Vulnerability of Children with Disabilities. South African Health Review 2006. Pg. 275

<sup>59</sup> Philpott, S. Pg. 273

from Sisizakele.<sup>60</sup> In October, a student from Sisizakele did not return to classes after holiday because she had been battling with repeated bouts of illness. She was checked into the hospital on a recurring basis over a period of two months and each time a different diagnosis was made. When none of the treatment made her well, and the diagnoses were obviously not addressing the whole issue, there was no referral to a specialist nor was there a complete range of blood tests done. Despite the fact that her health was not improving as it should have been, according to the diagnoses and treatment prescribed, little was done to look deeper into her health history or to explore other possibilities. The final diagnosis made was tuberculosis, three days before death. She was twelve years old.

The immense frustration felt by those close to her stemmed from the question of why stronger efforts were not made to explore other options when such little improvement in her health was seen over a prolonged amount of time. Just before she passed away, the possibility of leukemia surfaced. This diagnosis could have easily been tested for and explored early on in her treatment. The doctors treating her could have spoken with those caring for her while at the school and at home for any unusual symptoms that may have been noticed. The therapy department could have been consulted for any knowledge they may have had concerning her history and potential side effects of her disability. A health team that represented all of these angles could have been formed and in combination with more extensive testing, diagnoses could have been ruled out until the real one was determined. It cannot be suggested with any certainty that better communication would have saved this student's life. However, if communication would have been made a priority, at least those close to her would have the peace of knowing that everything that could have been done to help her was at least attempted.

The important implication of this story is that effective communication in healthcare can save lives. Proper health care cannot be delivered or realized without collaboration between everyone involved in a patient's care. This collaboration may well include people outside the medical field whose knowledge bridges gaps that practitioners fail to recognize. Each individual factor contributing to health needs to be viewed as a single part of a whole, and be approached with the bigger picture in mind.

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<sup>60</sup> Informal Conversations held with Lorato Jood and Leah. Sisizakele Special School. November 19-November 21, 2007.

## **The Right to Education**

The first policy that the post-apartheid government adopted which explicitly states that all children have an equal right to education, was the Convention on the Rights of a Child. Article 28 states that all children have the right to education, and Article 23 explicitly protects disabled children by stating that they must be offered education that ensures “the child’s achieving the fullest possible social integration”.<sup>61</sup> With the adoption of this policy, the government recognized that disabled children needed to be protected and offered the same rights as other children. The government’s commitment to the right to education was further manifest in their inclusion of the right in the Constitution of 1996.<sup>62</sup> Similar to the CRC policy, the Bill of Rights includes the right to basic education and freedom from unfair discrimination on grounds of disability.<sup>63</sup> With the ratification of the new Constitution, the right to education was given equal precedence as the rights to health, life and equality.

In the same year, the South African Schools Act of 1996 introduced a new inclusive education policy that would effectively take disabled children out of isolated special schools and into mainstream schools. Special schools were only accommodating 20% of the learners with special needs, which left as many as 280,000 disabled children across the country unaccounted for in schools.<sup>64</sup> This act made it a law for public schools to admit all learners and provide the necessary educational requirements without discrimination.<sup>65</sup> Although this commitment sounds well intentioned, it is limited by the stipulation that public schools are required to provide the necessary resources only “where reasonable practical”.<sup>66</sup> This safeguard is still being criticized today for effectively giving schools an excuse not to admit special needs students. Three years after this act was passed, the Department of Education published a White Paper entitled, *Special Education: Building an inclusive education and training system*. This document expressed how the department intended to implement the Schools Act. It further stressed that all children are capable of learning, and the right to education must not be determined by ability.<sup>67</sup> Implementation of the inclusive education policy, as outlined in the white paper, was to be phased in over a twenty year period.<sup>68</sup>

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<sup>61</sup> UN Convention on the Rights of a Child. Article 23

<sup>62</sup> Constitution of the Republic of South Africa, 1996. Chapter 2 Bill of Rights

<sup>63</sup> Constitution of the Republic of South Africa, 1996. Chapter 2 Bill of Rights

<sup>64</sup> Education White Paper 6: Special Needs Education. July 2001 Department of Education.

<sup>65</sup> South African Schools Act 1996. Chapter 2, Section 5.

<sup>66</sup> South African Schools Act 1996 Chapter 2, Section 5.

<sup>67</sup> Education White Paper 6: Special Needs Education. July 2001 Department of Education.

<sup>68</sup> Education White Paper 6: Special Needs Education. July 2001 Department of Education.



Today, the right to education for disabled children is being further defended by the new Children's Bill. The first bill was passed in 2005 but amendments were made by a range of organizations, and the amendment bill is now going through the legislative process.<sup>69</sup> One thing that it emphasizes, which failed to be addressed in other policies, is the necessity of Early Childhood Education for disabled children.<sup>70</sup> Constant stimulation in the formative years (in this case 0-9) is crucial for all children, and for disabled children the level of stimulation during this period could determine their level of function for the rest of their lives.

Together, these three documents guide the Department of Education as they attempt to realize the right to education for all disabled children. The next section provides the findings on how that right is being realized at Sisizakele Special School. Both the strengths and weaknesses of the school are identified and addressed.

### Findings at Sisizakele Special School

Thanks to the hard work of the team involved with getting Sisizakele operating, as well as the current staff, there are 39 kids getting the chance at an education that otherwise would have been a dream. Sisizakele is the only institution in the district realizing the right to education for disabled children of school going age.<sup>71</sup> The time spent at Sisizakele highlighted the strengths of their program as well as weaknesses that could be addressed and improved upon. Realizing the dearth of resources the school has to operate with, the suggestions for change are limited to those which can be carried out without requiring additional resources which may be unattainable.

### Strengths

The school has succeeded in creating a healthy environment in which the children are able to live. In addition to having their right to education realized, they are afforded the rights to basic nutrition, shelter and basic health care which are all found in Article 28 of the Constitution.<sup>72</sup> It is also a place where the children are able to be independent and free to move around using their own modes of transport, whether that be through walking, crawling, or a wheelchair.<sup>73</sup> This kind of independence and safety is not something many of them get to

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<sup>69</sup> Childrens Institute, University of Cape Town

<sup>70</sup> Childrens Amendment Bill Chapter 6, section 92.

<sup>71</sup> There is another school that is just starting up, that admits learners who have passed the typical school going age.

<sup>72</sup> Constitution of the Republic of South Africa, 1996. Article 28 (1)

<sup>73</sup> Based on observations made on November 6, 2007 at Sisizakele School.

experience at home due to physical and social barriers. Another very positive aspect of the schools setting is that it offers the kids a sense of companionship with people who face similar challenges. The way the kids interact and support each other is absolutely vital to their social growth and a strong sense of self. In discussing their move from a mainstream school, one student expressed their feelings about the schools sense of community in the following way; “I like to have more people able like me [here]. [Before] I was the only one and everyone else was walking with their feet”.<sup>74</sup> This sense of belonging is very important for the child’s self esteem which impacts on their school performance.

The staff must also be commended for how far they have come in such a short period of time. The school has only been operating for five years, but many children have made a great deal of progress, even with few resources available. One teacher expressed that, “a lot of kids have come a long way”.<sup>75</sup> This progress was also highly touted by one of the volunteer mothers at the school, who has seen her child constantly improving. She expressed satisfaction with her child’s experience at Sisizakele because, “he improves in writing and walking and other things like playing with other children”.<sup>76</sup> It is through these individual improvements that the children start to realize their potential.

As the only school catering to disabled children, Sisizakele has also recognized the need to expand. Despite their limited resources they are planning to increase their numbers by as soon as next term.<sup>77</sup> The current plan is to accommodate ten more resident students and ten students who are able to commute on a daily basis.<sup>78</sup> The current hostel situation will not allow for any more than ten additional residential students. Eventually the school hopes to offer classes up to the level of matriculation, as well as develop a skills development stream.<sup>79</sup> This is an ideal situation that will only be realized through a commitment from the department of education to expand the school to accommodate the wide range of needs the students have.

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<sup>74</sup> Student, Sisizakele Special School. November 14, 2007. 2:15 pm.

<sup>75</sup> Data from an informal conversation with Leah on November 29 at her home.

<sup>76</sup> Volunteer Mother at Sisizakele Special School. November 26, 2007. 1:30 pm

<sup>77</sup> Information from Principal Lorato Jood. Sisizakele Special School. November 16, 2007. 8:45 am

<sup>78</sup> Information from Principal Lorato Jood. Sisizakele Special School. November 16, 2007. 8:45 am

<sup>79</sup> Principal Lorato Jood. Sisizakele Special School. November 16, 2007. 8:45 am

## Weaknesses

It was found that at Sisizakele, “the main objective is to produce a person who successfully participates in the economy and society”.<sup>80</sup> The amount of time spent doing academic work in the classroom seemed inadequate to make this objective a reality. The morning session, which lasts approximately two hours, was typically the only time reserved for academic work.<sup>81</sup> It is important to recognize that because the school caters to such a wide range of disabilities and levels of function, it is very challenging to cater to all of the needs. As the principle put it, “delivery [of the curriculum] is determined by the child”.<sup>82</sup> This approach is appropriate as long as the delivery is not limited to the needs of a few children. One student expressed their frustration at being unable to progress each year by saying, “Since 2005 I was in grade three and in 2006 I was in grade four, but I am still in grade four. And next year I will be in grade four”.<sup>83</sup> Without seeing the potential for progression, some children may be unmotivated to work hard.

One major contributor to this slow progression was found to be the difficulty in adapting the mainstream curriculum to fit the needs of the school. One teacher expressed that, “there is not enough knowledge about the curriculum”.<sup>84</sup> Due to their special needs, the students are not given typical assessments, and so their progress is not strictly and consistently measured. For some students, it was found that this lack of structure resulted in their academic progress being slowed. Teachers aim to balance the time spent on academic work and time spent on skills work, but it was found that academic work could be made more of a priority.<sup>85</sup> The principal stated that “The goal is to have a full fledged school with an academic stream and a skills development stream”<sup>86</sup> In order to begin moving towards this goal, an effort could be made to separate those who need to be more academically challenged from those who would benefit more on skills work. Making that distinction would allow those who are able to make academic progress much quicker.

The lack of commitment from the government to properly fund the school was also noted as a major hindrance to making academic programs a priority. It was found that the school is still

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<sup>80</sup> Principal Lorato Jood. Sisizakele Special School. November 29, 2007. 9:00 am

<sup>81</sup> The study period included the end of the term for students, so the schedule followed in the last weeks may not represent the typical school schedule.

<sup>82</sup> Principal Lorato Jood. Sisizakele Special School. November 29, 2007. 9:00 am

<sup>83</sup> Informal Conversation with students at Sisizakele. November 29, 2007.

<sup>84</sup> Informal Conversation with Leah. November 29, 2007. 5:30pm

<sup>85</sup> Based on observations made at the school on November 14, 2007

<sup>86</sup> Principal Lorato Jood. Sisizakele Special School. November 16, 2007. 8:45 am

being funded on its enrollment numbers from 2005 when only 27 children were enrolled, and there are now 39.<sup>87</sup> This creates massive funding problems for the school. School fees are intended to cover the costs of the hostel, which is given no state funding, but many families fail to pay the fee on a consistent basis. The principle expressed, “If everyone is paying fees, I have enough money for food and it’s easy”<sup>88</sup> When the fees do not come in, funds are taken from the baseline budget given to the school and any potential for investing in new academic programs is lost. With the Department of Education failing to recognize the need for hostel funding, the school budget is continuously spent on basic needs rather than new academic programs.

#### Analysis: The Realization of the Right to Education

Sisizakele has in many respects succeeded in its mission to realize the right to education for disabled children in the area. With such a young institution, while their progress should be recognized, a commitment to improving the quality of education should be a priority. As one teacher put it, “we still have a long way to go”.<sup>89</sup> In order for the children to reap the greatest benefit, there should be a greater commitment to academic work for those who are able, and to skills work for those who are less academically capable. It is certainly not a distinction of the worth of the child, but separating the groups will allow each group to realize their potential through different avenues. The academic students should be pushed and challenged so that they may realize their full potential. The pace of learning must be reasonable, but it cannot be so slow that the children’s academic progress is impeded by attending the special school. As a result of barriers to access, many of these children start school much later than their peers, making it important for the timeliest progression through the grade levels as possible. A *laissez faire* attitude cannot be adopted simply because the students are not assessed as rigorously as they would be in a mainstream school.

Aside from Sisizakele and one other special school that caters to students past school going age, there are no other institutions in the whole Umkhanyakude district realizing the right to education for disabled children. When asked about the greatest challenge for disabled children in the area, Sonja Higham responded, “Definitely education, it’s very bad”.<sup>90</sup> There is not a single mainstream school in the local district that will accept disabled children, despite the

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<sup>87</sup> Information from Principle Lorato Jood. Sisizakele Special School. November 16, 2007. 8:45 am

<sup>88</sup> Principal Lorato Jood. Sisizakele Special School. November 16, 2007. 8:45 am

<sup>89</sup> Informal conversation with Leah at her home. November 29, 2007

<sup>90</sup> Sonja Higham. Mosvld Therapy Department. November 23, 2007. 12:15 pm

School Act of 1996 requiring them to do so. There have been no efforts by the Department of Education to educate and train local teachers in how to cater to a special needs child, and it has been eight years since the White Paper on inclusive education was published. This leaves the therapy department “grabbing in the dark for school[s]”<sup>91</sup> when they try to place a disabled child. A situational analysis that was done in 2002 found that there were 69 disabled children in the Mosvold Hospital service areas that were not attending school, exclusively because there were no schools willing to accept them.<sup>92</sup> Higham expressed that “the teachers have no clue how to handle them”, which is a reflection on the departments failure to take their policy off paper and into the schools.<sup>93</sup>

Until the Department of Education makes a real commitment to implement the policy that they crafted nearly a decade ago, the right to education for the majority of disabled children in the Umkhanyakude district will remain a dream. Without accepting and accommodating disabled students into a mainstream setting, an education that ensures “the child’s achieving the fullest possible social integration”<sup>94</sup> will not be realized. Only those fortunate enough to be admitted to Sisizakele will even have a chance at being educated and becoming a productive member of society.

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<sup>91</sup> Sonja Higham. Mosvold Hospital Therapy Department. November 20, 2007. 10:45 am

<sup>92</sup> DART Situational Analysis. Jozini District 2002

<sup>93</sup> Sonja Higham. Mosvold Therapy Department. November 23, 2007. 12:15 pm

<sup>94</sup> Convention on the Rights of a Child. Article 23

## The Right to Social Welfare

The right to social welfare is of particular importance for disabled children, because the stigma of their conditions often results in their being placed in the margins of society. In addition, many of their conditions leave them dependent upon others to ensure their active participation in society. Since the new government took power, there has been an effort to adopt and create policies which protect disabled children from being hidden and excluded from society. The first document adopted that protects the social wellbeing of disabled children was the UN Convention on the Rights of a Child. It recognizes that, “a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community”.<sup>95</sup> As the highest legal protector of a child, the state is again responsible for ensuring that these conditions be realized.

The Constitution reaffirms the commitment to promote social inclusion of disabled persons in its stipulation that, “the state cannot unfairly discriminate directly or indirectly against anyone on the grounds of disability”.<sup>96</sup> The most current legislation being considered, which puts a large emphasis on a child’s social welfare, is the Children’s Act. In regard to disabled children it states that consideration must be given to, “making it possible for the child to participate in social, cultural, religious and educational activities, recognising the special needs that the child may have”.<sup>97</sup> Although this Act is not expected to be implemented until 2008<sup>98</sup>, it indicates what direction legislation on the topic of social welfare is going in the near future. Until the new legislation is passed, the Convention on the Rights of a Child and the Constitution remain the guiding policy in matters of social welfare and inclusion for disabled children.

Another important aspect of social welfare for disabled children is their access to the care dependency grant. The grant was first offered in 1992 as part of the Social Assistance Act.<sup>99</sup> It is currently valued at 870 rand per month to those who qualify.<sup>100</sup> The government defines the eligible child in this way; “a child between 1 and 18 who requires care due to his/her severe

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<sup>95</sup> UN Convention on the Rights of the Child. Article 23

<sup>96</sup> Constitution of the Republic of South Africa, 1996. Section 9 (3)

<sup>97</sup> Childrens Act 2005. Chapter 2, Section 11. “Children with disability or chronic illness”.

<sup>98</sup> Children Institute, University of Cape Town

<sup>99</sup> Lund, F. Presentation on Social Welfare. School for International Training. Durban, South Africa. September 27, 2007.

<sup>100</sup> Lund, F. Presentation on Social Welfare. School for International Training. Durban, South Africa. September 27, 2007.

intellectual or physical disability can be regarded as care dependent”<sup>101</sup> Although this definition may lead one to believe that it is quite clear who should receive the grant, there are a number of requirements that limit the number of people who are able to access it. The requirements for eligibility are listed below:

- The applicant must be a parent, primary caregiver or foster parent of the child who requires and receives permanent care or support services.
- The child must be a South African citizen. However, foster parents need not be South African citizens.
- The child may not be cared for on a 24-hour basis for a period exceeding six months in an institution that is fully funded.
- Both the applicant and the child must be resident in South Africa.
- The child must be between one and 18 years old.
- The applicant, spouse and child must meet the requirements of the means test. In 2004 the requirements stated that the income of the entire family should be less than R48 000 a year or R4 000 a month, and less than R17 760 per year for the child.<sup>102</sup>

The well being of thousands of disabled children in South Africa rests on their family’s ability to access this grant. If properly administered the grant can be a “powerful poverty alleviating mechanism” for the families of disabled children who face an extreme scarcity of resources.<sup>103</sup> Findings concerning the realization of the right to social welfare at the study sites are reported in the following sections.

## Social Inclusion

An issue that arose in speaking to a group of students at Sisizakele was the common feeling of social exclusion. The students who had previously attended a mainstream school described how they preferred going home everyday and seeing their families. At Sisizakele, many of the students are far from their homes and rarely see their families. One student expressed, “I am crying when my mother doesn’t phone me”.<sup>104</sup> This exclusion from family weighed very heavily on the students, and their opinion of the school was highly influenced by

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<sup>101</sup> Hollingshead, J. “Care Dependency Grants”. Child Health for All: A Guide for Southern Africa. Oxford University Press. 2001

<sup>102</sup> South African Government Services. Care Dependency Grant.

[http://www.services.gov.za/en\\_za/caredependencygrant.htm](http://www.services.gov.za/en_za/caredependencygrant.htm). Accessed 30 November, 2007

<sup>103</sup> Landsdown. Page 23

<sup>104</sup> Student, Sisizakele Special School. November 14, 2007. 2:15 pm.

that factor.<sup>105</sup> The situation in the district ultimately offers disabled children an ultimatum of either not being educated or seeking education at a special school that is socially exclusive. When choosing education means losing the ability to interact with the general population, the right to “conditions which...facilitate the child's active participation in the community”<sup>106</sup> are blatantly violated.

### Uptake of Care Dependency Grant

The uptake of the care dependency grant among the families of disabled children at the study sites was found to be good. Every child currently attending Sisizakele special school is receiving the grant, part of which is intended to go towards to the 300 rand per month school fee.<sup>107</sup> This high uptake among the students is likely because each of them was referred to the school by their home hospital, which aided them through the application process. It was found that the Mosvold therapy department is in fact the primary way through which families access the grant in the study area. The department has welfare days on a weekly basis in which the day is devoted to assisting people in accessing grants, including the care dependency grant.<sup>108</sup> As a result, all of the mothers attending support and therapy groups at the therapy department are receiving the grant. Mothers who are not getting the grant tend not to come to the groups because of the cost of transport.<sup>109</sup> Although the high uptake at the study sites implies that disabled children are benefiting from the grant, it was discovered that the actual use of the grant money is an issue of concern.

The care dependency grant was created as a means to alleviate the extra costs of caring for a severely disabled child. It is intended to be used by families to ensure that their disabled child be fed and clothed, live in adequate housing and attend school regularly.<sup>110</sup> Despite these objectives, it was found that often times the grant was not used for the direct benefit of the child. Even though all of the students at Sisizakele are receiving grants, the principle reported that she never receives more than half of the school fees on a monthly basis.<sup>111</sup> That means that not even

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<sup>105</sup> Informal Conversation with Students at Sisizakele. November 24, 2007

<sup>106</sup> Convention on the Rights of a Child. Article 23

<sup>107</sup> Information from Conversation with teacher Leah. November 6, 2007. 8:30am

<sup>108</sup> Sonja Higham. Mosvold Hospital Therapy Department. November 20, 2007. 10:45 am

<sup>109</sup> Occupational Therapist. Mosvold Hospital. November 6, 2007 11:00am. The statement that all mothers attending groups are receiving the grant is based on asking the therapist in charge of the each group if the participants were receiving the grants.

<sup>110</sup> Social Welfare. Paralegal Advice. Accessed at [www.paralegaladvice.org.za](http://www.paralegaladvice.org.za) 30 November 2007.

<sup>111</sup> Information from Principle Lorato Jood. Sisizakele Special School. November 16, 2007. 8:45 am



one third of the grant is going towards the child, who is cared for on a 24 hour basis by the school. The children at the school sleep on the floor, “two people in one space”<sup>112</sup>, because the mattresses they have are so worn down that they are essentially useless and the cost of beds is far outside the means of the school. These conditions do not describe a, “standard of living adequate for the child's physical, mental, spiritual, moral and social development”.<sup>113</sup> It is reasonable to assume that if the child's family is benefiting economically from the grant in any way, the child will also benefit, even if it is indirectly. However, in situations where the child is not being cared for at home, it seems rational to require that at least a portion of the money go towards their care.

It was found that one problem that keeps the grant from being allocated properly is a lack of communication between departments. This was cited as one of the biggest challenges faced by the therapy department.<sup>114</sup> The Welfare Department saying the grant must be used to benefit the child while the Education Department is saying a family cannot be forced to pay school fees if they are not able.<sup>115</sup> Many of the families in the area depend on the grant as their only income and as a result, “Most of the mothers would rather get the grant and use it for their families instead of trying to pay for their child to attend a special school”.<sup>116</sup>

Although it is clear that there is a misappropriation of the funds, there is very little being done to apprehend those misusing the grant. There is only one social worker employed by the hospital to cover everything except the VCT services.<sup>117</sup> In addition, there is very little interface between the social worker and the therapy department. The therapy department does make an effort to intervene when they come across a situation where a child is not being cared for properly, but this is admittedly rare.<sup>118</sup> When asked about the follow up of grants, Sonja Higham responded, “we try to make sure that the child is being cleaned, cared for, and is schooling”, yet she explained that it is difficult for their department to take on the duties of social welfare.<sup>119</sup> Another issue cited by Sonja is that when a disabled child is found to be mistreated or poorly cared for, there are few options to protect them. “No orphanage or anyone wants to take them.

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<sup>112</sup> Informal conversation with students at Sisizakele. November 24, 2007

<sup>113</sup> Convention on the Rights of a Child. Article 27

<sup>114</sup> Information from Sonja Higham. Mosvold Hospital Therapy Department. November 20, 2007. 10:45 am

<sup>115</sup> Information from Sonja Higham. Mosvold Hospital Therapy Department. November 20, 2007. 10:45 am

<sup>116</sup> Occupational Therapist. Mosvold Hospital. November 13, 2007.

<sup>117</sup> Sonja Higham. Mosvold Hospital Therapy Department. November 20, 2007. 10:45 am

<sup>118</sup> Information from Sonja Higham. Mosvold Hospital Therapy Department. November 20, 2007. 10:45 am

<sup>119</sup> Information from Sonja Higham. Mosvold Hospital Therapy Department. November 20, 2007. 10:45 am

It's a huge problem".<sup>120</sup> Taking the grant away will only further disadvantage them by frustrating their caregivers and deepening the effects of poverty.

#### Analysis: The Right to Social Inclusion and Welfare

The data collected from the study sites suggests that the right to social welfare is not being properly protected and acted upon. It seems evident that the primary obstacle to realizing the right is a lack of resources provided by the government. The children at Sisizakele spend nearly every hour of every day behind the gates of the property. There are efforts made by the staff to plan excursions, but the last school wide excursion was in 2005. Without even enough resources to provide each child with a proper mattress, spending funds on social events becomes a very low priority. An educational experience that so dramatically restricts students from being involved in the community does not encourage the social integration that the CRC suggests should be realized through education. The department of education has to recognize that if these children are schooled in an environment where every child is disabled and they are unable to experience life in mainstream society, even if their schooling is successful their social and behavioral skills may prevent them from functioning among the general public. There desperately needs to be a budget for activities outside the school grounds so that both the children and the public can learn to interact with each other amongst their differences. The "full and decent life"<sup>121</sup> that each disabled child is meant to experience, as outlined in the CRC, cannot be realized from behind a fence.

The study found that the therapy department at Mosvold is doing an excellent job of assisting families in acquiring care dependency grants. In an area where the economy is struggling, the grant is vital to the well being of many families. The commitment to service delivery observed among the therapy staff certainly deserves commendation. The concern is whether or not the funds are actually being used to improve the quality of life for the child. If there is no infrastructure to ensure proper use of the funds, the grant becomes a way in which disabled children are used for the benefit of others. One social worker for an entire hospital service area is not adequate to address the task of protecting children's rights. One major obstacle is finding workers who are willing to live and serve in rural areas, and that obstacle is certainly noted. It does not excuse however, the need for a commitment from the Department of

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<sup>120</sup> Sonja Higham. Mosvold Hospital Therapy Department. November 20, 2007. 10:45 am

<sup>121</sup> Convention on the Rights of a Child. Article 23

Social Welfare to develop a system that checks the living conditions of grant recipients to ensure its proper use. The children are unable to defend their own right to social welfare, and without a proper auditing system many fail to receive any benefit from the grant which is intended to improve their quality of life.

## Conclusions

The quality of life experienced by disabled children is largely determined by the rights they are granted and who ensures that those rights are realized. One advocate writes, “Whilst all children experience discrimination in the exercise of many rights there is a double jeopardy facing disabled children, a jeopardy compounded still further for non-white disabled children”.<sup>122</sup> This study has provided evidence that reaffirms the truth of this statement for the children observed. Rights to health, education and social welfare are still struggling to be realized, especially in rural areas where services delivery is inconsistent.

The data from this study suggests that the rights of disabled children are protected well on paper but not in reality. The right to health was found to be the most realized and accessible among those studied, while the right to education was being realized by only one institution in the whole district. The right to health can really only be realized if the guardian of the child is willing to access the services that are offered by the hospital. The therapy department studied was well developed and offered rehabilitation groups, but if the guardians are not willing to invest the time to attend, there is little more that can be done by the therapy team. Thus the onus is both on the state and the guardian to make the right a reality. At Mosvold, there are improvements that can be made by both parties that will help the children reach their potential. However, the responsibility of the state was found to be much greater in realizing the right to education, because if there are no schools accepting the children, there is little that can be done by the guardian. It is purely the responsibility of the state to provide training and resources that will allow for the inclusion of these students into mainstream schools. The promise to accommodate the students was made by the department in their White Paper eight years ago, but school doors are still not open for disabled children in the Umkhanyakude district.

The impact of leaving an entire population uneducated is very negative for the whole of society. Excluding disabled youth from an education forces them to become a member of society who depends exclusively on the social welfare system of the state. Even the social welfare system may not be enough to protect them, as this study found it common for grant money to be used for purposes other than those intended by the grant. Education is a way to break the circle of dependence upon others and the state, but the department has failed to even begin implementing an inclusive system in the district studied. It is debatable that so many resources

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<sup>122</sup> Lansdown. Pg. 36

should go towards children whose potential to contribute to society economically is far less than the average student. This may perhaps be what is keeping the Department of Education from investing in their inclusion policy. They are unsure whether the inclusive environment they envisioned in their policy is really the best use of their resources. Through observations done in this study it has become apparent that even though the cost of implementation may be high, the moral value in realizing the rights of the most vulnerable members of society speaks volumes about the integrity of a society.

There is potential in the future for disabled children whose rights are not yet being realized, but it rests in the hands of provincial and district officials who job it is to implement the current policies. The South African government has done far more to defend their disabled population than most developing countries have. There are extensive policies, some of which has been cited in this study, that address the rights and needs of disabled persons. In order for these policies to be realized there needs to be budgets and resources set aside at the district and provincial levels that explicitly go towards the realization of the policies. If the policy remains at a national level it is unlikely to see changes and the struggles will endure.

Finally, within the progressive framework of disability rights that South Africa has developed, there needs to be a place for the voices of children to be heard. Disabled children are struggling now because, “the adult world is not yet sufficiently willing to accept that children, including disabled children, have a right to be heard and that they have perspectives, views and experiences which must inform legislation, policy-making and service delivery”.<sup>123</sup> These children need to be made aware of their rights and become active members in the implementation of policy, advocating for changes that will transform lives.

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<sup>123</sup> Lansdown. Pg. 37

### **Recommendations for further study**

This study could be expanded on or followed up in two different ways. In order to get a deeper understanding, rather than look at three different rights it might be effective to pick one of them and complete a more in depth study. This might include case studies of individual children that provide detail into how that single right affects their life over a period of time. This kind of study may also be able to identify effective and ineffective methods of policy implementation based on the case studies.

Another option would be to pick a specific program or topic at either Mosvold Hospital or Sisizakele Special School and do a more in depth study of that program and how effective it is in accomplishing its goals. Topics may include the adaptation of the mainstream curriculum at Sisizakele or the rehabilitation groups at Mosvold Hospital. By studying a single program, the researcher would be able to measure its impact more clearly than if doing a survey of all the programs. Ways to improve the program to increase its effectiveness may also be identified.

Contact details for each institution are listed below:

Ms. Lorato Jood – Principal Sisizakele Special School

[Sisizakele@polka.c.za](mailto:Sisizakele@polka.c.za)

Mrs. Sonja Higham – Manager, Mosvold Therapy Department

[nontokozo.mabuza@kznhealth.org.za](mailto:nontokozo.mabuza@kznhealth.org.za)

## **Essential Texts**

The following publications are useful for anyone interested in the field of child disability in South Africa.

Disability and Social Change: A South African Agenda: This book, published in 2006 by the Human Sciences Research Council, gives an unprecedented look at the most current information about disability in South Africa. It aims to establish an attributive link between oppression and disability. It does this by looking at different populations of disabled people, and explains how society and the built environment are designed to cater only to the able-bodied population. A number of authors contribute to the publication, which brings disability in South Africa into the realm of academic discourse, while also providing an excellent resource for disability research. This publication provided the study with a great deal of background information on the disability rights movement in South Africa.

Census 2001: Prevalence of Disability in South Africa: This publication gives any researcher the most current census information regarding the prevalence of disability. It is essential to understand the breadth of disability by sheer numbers before embarking on specific research on the topic. This is a well organized article that is easy to read and gives the researcher an excellent sense of the current situation of disability.

### Vulnerability of Children with Disability: The Impact of Current Policy Legislation and Policy:

This is a publication from the South African Health Review 2006. It looks at the particular vulnerabilities of disabled children and explores various factors that create and perpetuate these. This is particularly useful because it covers the full spectrum of disabilities both physical and mental. Impairment and exclusion are looked at as determinants of disability in children. It also presents information about the limited research done in regard to prevalence of childhood disability. The lack of data on prevalence can be a hindrance to the researcher of childhood disability, but this publication does an excellent job of compiling the information that is available. This publication was useful for this study because it was a good reference for comparing struggles for disabled children found at the study sites to struggles felt by children nation wide.

Disabled Children in South Africa: Progress in Implementing the Convention on the Rights of the Child:

This is a report that was commissioned by Disability Awareness in Action, to explore the implementation on the United Nations Convention on the Rights of a Child as it relates to disabled children. The UN Convention remains one of the primary pieces of legislation adopted by the South African government which protects the rights of disabled children. This is a very detailed report that looks at the policies in the convention and how they are being realized in the health, education, social and human rights sectors. It explains what rights the convention conveys and how they are or are not being realized. Although this was published in 2002, many things are still true today and anyone reading the document will come away with a really good picture of how the convention has impacted the lives of disabled children in South Africa.



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Conversation with 15 year old student at Sisizakele. Bhambanana, KwaZulu Natal South Africa. November 14, 2007. 2:15 pm

Conversations with Doret, Occupational Therapist at Mosvold Hospital. Ingwavuma, KwaZulu South Africa. November 6 and November 13, 2007.

Conversation with Leah, teacher at Sisizakele Special School. Bhambanana, KwaZulu Natal South Africa. November 29, 2007. 5:30 pm

## Appendix A: Daily Log

Tuesday, November 06 (7:30 am-2pm)

I began my day with a teachers meeting in the faculty room of Sisizakele. The school day began at just past 8, and I accompanied Leah in her grade 4 classroom. I was introduced to the class of 9 students, and attempted to begin learning their names. The students were learning North, South, East and West and tried to apply them to their knowledge of the province in South Africa. The students were very good with pointing to the directions, and were able to identify all 9 provinces. I left the school around 9am to head to Mosvold.

At Mosvold I was greeted in the therapy department by a room full of children and adults. The department is a single room which has one main space to work in, and 3 “rooms” divided by curtains. Doret, the Occupational Therapist was busy running the whole department single handedly. I stayed for the cerebral palsy support group for mildly affected children. There were 7 kids all accompanied by female caregivers. The focus of the group was on using small flash cards to get the children to identify objects and learn colors. The OT, with the help of a translator, spent a great deal of time trying to explain to the mothers the appropriate way to use the cards so that the children would actually benefit. It seemed that there was only a bit of understanding among the mothers, and not a great deal of commitment on their part to work with the cards at home. The OT did say however that the women who showed up for the support groups were the most dedicated to their child’s care. She also noted that every one of them was receiving the care dependency grant which is largely why they are able to come to the monthly group.

Wednesday, November 07 (8:00am – 2pm)

I spent all day today at Sisizakele. When class time started around 8:15, Leah began a math lesson. The students were learning about patterns and multiples of numbers. After that I spent some time going through a Physiotherapy Manual for all of the students, which was compiled by a group of Dutch physiotherapy students who spent four months at the school this spring. I was interested at finding the most common diagnoses, and if the recommendations were being followed. The most common diagnoses were found to be cerebral palsy and spina bifida. Each student had an extensive evaluation done, but from what I could gather there just isn’t the staff to follow through with the therapy. I also went through the therapists “black book” which was ideally supposed to be used as a means for the different therapists who visit the school to communicate what they did with the students. Only a little bit of documentation had been done. One audio therapist expressed frustration that there is really little to no progress that can be made in one or two visits monthly. The attention the kids need really has to happen on a daily basis in order for progress to be made.

Before lunch I did arts and crafts with the kids who were able, and we made lanyard key chains. The kids seemed fairly interested but I think they got bored towards the end. After lunch I went back and forth between playing on the playground with one group and listening to another group practice singing. Finally, I asked Leah if she thought I could use some leftover paint they had to paint “Welcome to Sisizakele” in entry way of the reception area, and she said that sounded great and she would have to run it by Mrs. Jood, the principle.

Thursday, November 8 (8-2:30)

I began the day at Sisizakele. The teachers were busy trying to get a few of the kids to a function at another school so did my best to keep the level four class busy. I got an atlas out and was explaining to the kids where I was from, and we reviewed the names of the 7 continents. Again, they all seem very eager to learn. At about 9:30, I was picked up by Sonja to go with her and the translator on some home visits. We unfortunately didn't get to see any children, but it was still a very interesting trip. We visited four homes, which were spread very far apart on terrible roads so it was pretty slow going. The first home they were checking on a gogo. We found her on the floor on a mat in a single room house. She was in very bad shape. The family hadn't been exercising her at all so her arms and legs could hardly be moved at all they were so stiff. She also had a wheelchair but nobody was bothering to get her up to go outside. It was very hard to see someone in such bad shape. The therapist told the family that the gogos pension would be taken away from them if they didn't start using it to benefit her. Two of the other gogos we visited had had strokes and were just being checked on to see how their recoveries were going. Both were able to get up and walk about, and seemed to be in fairly good health. One gogo made it quit clear she didn't like that she had to give up her utshwala! The last home was again a stroke patient who wasn't doing nearly as well and sat on the ground with her legs contractured nearly all day. I really enjoyed the experience and was still able to get some information from Sonja about grants and other issues that dealt with child disability and the role the hospital plays in rehabilitation.

Monday, November 12 (8:00am-3pm)

I began the day at the school where I met the principal, Ms. Jood. Today was her first day back from being ill, so it was nice to get to meet her. I got permission from her to begin my painting project in the front reception area of the school. I am going to paint "Welcome to Sisizakele". I began my work on measuring everything out and getting the letters traced on the wall. Hopefully I will get that nearly done by the end of the week. I left the school at about 10:15 to head with Sonja to the clinics.

We visited two different, what I believe are considered, bush clinics. There was no clinic per say but just Sonja and the translator meeting at the designated spot (community hall and church). These clinics are visited the second Monday of every month. Sonja had medications to give a number of the patients. None of them had major problems, but it was rather just a check up and a time to get pills. Most of the patients complained of general pain, which Sonja said she could really do little to help. One lady who was quite young was presenting with symptoms of arthritis and Sonja said it is seen more common in younger populations here because they put a great deal of stress on their bodies and joints lifting and carrying very heavy things. One of the patients had a son there who Sonja said was mentally disabled. He appeared to be in his teens. She explained that he had been seen a number of years ago, and arrangements were made for him to attend a special school which is about 4 hours away. The family didn't end up taking him and as a result he has never had any schooling. It was very sad to hear this, but I think it exposed me to what happens to all the kids who aren't fortunate to get into a special school and who can't be appropriately cared for in a mainstream school.

Tuesday, November 13 (8:00am-3:00pm)

I began the day very briefly at Sisizakele where I put some final touches on the prep work for my painting project. I spent the rest of the day at Mosvold. I first sat in on the CP severe group with one of the physiotherapists. She was a native Zulu speaker, so it was a bit more difficult to follow along but I enjoyed observing. The group had 3 children for the majority of the time and then 2 more showed up about fifteen minutes before the group was over. None of the children had speech abilities. At the beginning of the group the therapists asked the mothers about what they had worked on over the last month. After it was obvious the first child had improved, she got applause from the others. The mothers seemed very interested in the work they were doing and very motivated to learn. The therapist said that she noticed an improvement in two of the kids since last month. The mothers worked on therapy balls, primarily aiming to relax their child's muscles which were all very contracted as a result of their CP. The kids were also very responsive and seemed to be benefiting from the stimulation, as their smiles were very big throughout the group time. I did notice that the mothers in this group seemed a lot more responsive to the therapists than the mothers in the CP moderate group. I found myself wondering if having a native zulu speaker teaching them put them more at ease.

Later in the afternoon I went with Speech Therapist to the nursery where she was checking on 8 day old twins who were premature. The therapist was checking on their sucking reflex. After that I accompanied two of the therapists to the Paeds ward where they were doing a stimulation group. They were essentially teaching the mothers how to play "memory" with their kids using colors. There were about 8 kids there with their mothers. The ward was a bit smaller than I expected. Again it was determined that the majority of the kids there don't go to school at all. The therapists were trying to get across to the mothers that they must try and teach their children things while playing with them, because they are their only teachers if they aren't going to school.

Wednesday, November 14 (8-2:30)

I spent the whole day at Sisizakele today. I started off the day back tracking a bit and erasing what I had ready to paint because Ms. Jood changed her mind about how she wanted it done. No problem though, I just erased as much as I could and moved to the new place. I spent most of the morning working on sketching out the letters in the new location. After the morning break I began working on a library organization project. They have quite a few books but they haven't ever been cataloged in any way. I wrote them all down in alphabetical order and typed up a list of books.

The afternoon was kind of slow today, I think because it was so hot. I did get a chance to ask one of the students a few questions about her experiences and that was a good opportunity. She is 15 years old now and has been attending Sisizakele for about 3 years. She attended a primary school before transferring, but she told me that the teachers didn't treat her very well and her mother made her move schools. Although she liked the primary school because she got to see her family everyday, she did say she enjoyed having more people who are able like her at Sisizakele. She was the only one in a wheelchair at her previous school. It was nice to talk to her and get a students perspective on their own situation.

Thursday November 15 (8:00 am- 1:00pm)

I was at Sisizakele again today. I spent the morning session with Leah in her classroom. The kids were correcting their work on directions (North, South etc..) Some of them really understood the concept while others seemed a bit lost and their answers were more of a guess than a thought out answer. Most of the students were also somewhat unsure of themselves. When they gave the right answer and Leah looked at them a bit funny, they would immediately change their answer! She explained to them that north will always be north no matter how she responds to their answer, so if they know their answer is right they should stick with it. After that Leah had them name all the countries they could think of.. They are also very good with knowing and naming the 9 provinces in South Africa, and even their capitals.

Ms. Jood was unable to make it in today because one of the students is very ill in the hospital, so the painting project is on hold for now. I spent a bit more time cataloging the library books, and I am now waiting for stickers to put on the books with their appropriate numbers. I spent the rest of the afternoon working with the choir, learning songs for the Christmas program they perform when their parents come to fetch them. We learned Silent Night and Oh Come All Ye Faithful, both in isiZulu.

The teachers all left early after being called by Ms.Jood and told they should go to the hospital immediately to see the sick student because they probably didn't have a lot of time left. I stayed for about an hour longer working with the kids, and having those who were able read me a book in English. I had four students read the entire book with only a few mistakes. I was very impressed by this, and I plan to continue to read with them as much as possible to encourage them to speak the English they know, while learning more. There is little time spent learning English in the classrooms, because it is very difficult to cater to the different students' levels of proficiency. It will be nice for me to get to work with the ones who are really learning it well and encourage them to keep working with it.

Friday, November 16 (8-1)

Began the day setting up for a visit by a group of Americans with TOMS shoes. It's a company that donates a pair of shoes for every pair sold. South Africa was the destination for their second "shoe drop" and they brought 50,000 pairs to the country. After set up, I was able to talk with Ms. Jood a little bit and got a lot of great information about the school. She gave me the schools profile that she had just recently prepared, which answered a lot of my questions about the history of the school. She also clued me in on exactly how the school is funded and the how it creates a huge burden for the school to sort out independently with donors. Details of the conversation are found in the informal conversations appendix. After our conversation, I worked with the choir a little bit with the Christmas songs.

The TOMS group arrived at about 11 o'clock. There were about 8 of them that came to the school. The kids sang two songs for them, Ms. Jood gave a short presentation about the school and then the teachers sang a blessing. After the schools show, the group unloaded all the shoes and fitted each of the kids. I was able to use my zulu to help the group talk to the kids so that was also really fun. It was a great experience for the school and the group that visited and it was obvious that they were very touched by the children.

Monday, November 19 (8:00 am – 2:00pm)

I spent today at Sisizakele. I was given the responsibility of the grade four class in the morning, while Leah made arrangements with the other teachers for Wednesdays memorial service for the student who passed away last week. I first read the kids *The Lion, the Witch and*

*the Wardrobe* and tried to focus on getting them to recognize some new English words. The loved the book and looking at the illustrations. After we read together, I worked with one student at a time, having them read to me in English. I found that most of them were able to get through the books with very little trouble; however they struggled with understanding what they were reading. After every few pages I would have them stop and explain what they had just read to me. Each student needed quite a bit of help with this at first, as most of them could read the words but didn't really know what they meant. I found it to be very fun working with the kids on reading, and I think they really enjoy it too. All of them were very eager for their turn to read. I think reading and comprehension is an area that could definitely be worked on more in the school.

I spent the afternoon working with Ms. Sne and the choir, again preparing for Wednesday. After their practice, Ms. Jood had all the teachers, including myself, go and practice a few songs as well. I think until the memorial service is over, there will be little in the way of classroom work. After the teachers' practice I went and read with more kids until the afternoon was over. I am really hoping that by getting the library cataloged the students will have more access to the books and will read them on a daily basis.

Tuesday, November 20 (8:00 am-3:30)

At Mosvold, I first observed and participated in the Moderate Cerebral Palsey group. This classification is used loosely, as there was also a boy with downs syndrome and a girl with developmental delays. The group had 5 children and 5 mothers and was run by the speech therapist and a translator. The ages of the children varied quite a bit, but their activity levels and capabilities were very similar. First they reviewed what the group did last month, and two of the mothers had brought back the worksheet they had their kids do as homework. She then re-iterated the importance of children interacting with other children at home. This month, the group focused on how to make toys out of "rubbish". The kids used plastic water bottles, rocks, and pop can tabs to make rattles to play with. They also colored a piece of paper to decorate the outside... After the toy-making we did the Zulu version of head, shoulders, knees and toes, and I was quite proud to be able to join in!

I spent part of the afternoon speaking with Sonja and Doret about some of the challenges their department faces. They said that the biggest challenge is a lack of communication between people involved with the children's care. After our conversation I went to the Paeds ward, where a lady from an NGO was working with the mothers, using a picture book to show they how to talk to their kids about HIV. It was a book written by an HIV positive little girl from Holland and her mother. It's called, *Brenda Has a Dragon in her Blood*, and I thought it did an excellent job of getting the point across. I ended the afternoon in the nursery, where the same twins I saw last week were. They are still stable and are beginning to gain a little bit of weight. One of them is even to breast feed a little bit.

Wednesday, November 21 (7:30-1:30)

I spent the day at Sisizakele doing the memorial service for Sbongile. I arrived early to help get everything set up, and the service went from around 9:30 until 12. It was a nice service, and I think everyone in attendance really appreciated it. There was a lot of singing from the teachers and the school choir, and both the Shembe and Catholic priests were present. It's hard to see people saying goodbye to such a young girl whose death came far too soon. Following the service, the guests were served food that Ms. Jood had prepared. I stayed until everyone left and



then helped clean up the rooms. After everyone had cleaned up, everyone called it a day and headed home a bit early.

There was, rightly so, no time spent in the classroom today but hopefully now that the service is over there will be a bit more academic work done in the days to come.

Thursday, November 22 (8:00am- 2:00pm)

I spent the day at Sisizakele, and finally got to work on my painting project! Ms. Jood had the fabric and paints ready for me, and I got the majority of the project done. The final project should turn out very nice. I also got to spend a portion of the afternoon just sitting and talking to a group of about 8 students. It was amazing how much they opened up and were honest with me about their feelings of the school and their situations. It was very funny when they saw me write down some of the things they said they got really nervous and wanted to know if I was going to go and tell the principle on them. I was able to get a lot of insight into how they really feel about their school environment which was much different than my outsider's perspective of the schools operations.

I got to spend a little bit of time with a student reading just before the day was over. It makes me very happy that they are now asking to read to me, instead of me urging them on. It's amazing how much these kids really want to learn. They are especially interested in learning English, and it's really a privilege for me to get to work with them on it. The day ended with a promise to continue the reading tomorrow.

Friday, November 23 (7:30-12)

I started the day at Sisizakele, and just spent about an hour there before I headed for the hospital. I had promised two of the students I would come in early and read with them before I left today. We sat and read *Corduroy* together, and they alternated reading pages. They did quite well, and again I tried to stress their actual understanding of what they were reading.

I had a short day at the hospital today. The toddlers group was going on when I arrived and they were having their Christmas party. There were 9 kids and mothers in attendance. The majority of the kids had mental disability, and a couple had physical disability as well. Sonja was working with them on understanding body parts by decorating crackers with icing and making faces with candy. I got to sing "Ikhandu, mahlombe etc..." with them and I had a lot of fun with that. After the group ended I got to speak with Sonja a little bit. I tried to focus the conversation on the biggest challenges she felt were faced by disabled children in the area. She overwhelmingly said the biggest is in accessing education. The conversation was very informative and helpful for my study.

Monday, November 26 (8:00am-2:00pm)

I spent today at Sisizakele. I worked on my library organization project a little bit in the morning, but now I am just waiting for the stickers I need to finish the cataloging. After that I worked with the school choir learning more songs for the Christmas party on Thursday. The kids have such amazing beautiful voices and it is really fun to work with them. After the choir session I got a chance to talk to one of the volunteer mothers for a while and got a lot of good information from her. I was primarily asking about her experiences with her child before and after they started attending and volunteering at Sisizakele. I also asked questions about her access and use of the care dependency grant, and what kind of health care her child was given before he started attending school. The details of the conversation are in Appendix B #11. In my

time spent at the school I have seen how incredibly hard the mothers work and it was really nice to get to sit and talk with one of their stories.

The afternoon was spent just hanging out with the kids after their lunch time. We played on the trampoline and swing set and had a great time. At the very end of the day I got to finish reading a book I starting reading with two of the students on Friday. They continue to struggle a little bit with understanding what they are reading. It is very difficult for them to tell me in English what they just read about, so when I am reading with them I have them summarize for me in English after each page. I think it is so crucial for them to get reading time in every day, so I am happy to get to accommodate that while I am here.

Tuesday, November 27 (8:00am-2:30pm)

I got to enjoy a new experience at Mosvold today. A team of doctors from Durban is flown into the hospital monthly with a group called Air Mercy Services, run by the Red Cross. There was an orthotic specialist as well as a plastic and reconstructive surgeon seeing patients in the therapy department today. The orthotics specialist was fitting children and adults with new orthotic shoes and braces. The majority of the patients were adults though. The plastic surgeon was seeing patients who had a wide range of issues. Based on their condition, he either did surgery on them that day, or booked them for his next visit which will be in February. I got to go with him to the operating theatre to watch the surgeries he did today. We all got out scrubs on and spent about three and a half hours total in the theatre. The three cases he did today were a skin graft for a child who had been burned, a “z stitch” to restore function to a patient’s thumb which had been contracted by scar tissue, and a patient who had an issue with one of the tendons in a finger. Although none of them were very major surgeries, it was interesting to see how the surgery experience played out in a rural hospital. The theatre was similar to what I would have expected, and the facilities were quite nice. The surgeon from Durban and one of the community service doctors at the hospital are the ones that completed the surgeries, joined by a team of nurses.

Wednesday, November 28 (8:00am-2:30pm)

Today was my final day at Mosvold. I spent the morning in the nursery with the speech therapist, while she observed the babies feeding in order to see the strength and development of their sucking reflex. The twins which have been there the whole time I have been working at the hospital are doing quite well and should be going home soon. Each of the high risk babies will automatically be put in the care of the therapy department and their development will be checked until they are one year old. If they aren’t developing properly they will continue to work with therapy, but if they are fine they will be discharged. After the nursery, I was lucky enough to get to see a live birth! The woman was already pushing when we went in and the whole thing only took about ten minutes! The baby was healthy and screaming when he came out and was probably able to go home. It was such a great experience to see, and it made for a great last day at the hospital.

In the afternoon was the baby group Christmas party. There were 5 mothers and their babies there today. The babies were disabled in different ways, including downs syndrome and cerebral palsy. The group started with a discussion about the positive and negative aspects of the group that year. Each of the therapists and mothers gave their input about things they liked and things they wanted to change for the next year. It was a very informative conversation to observe, and I learned a lot about how the mothers learn from the therapy groups. They were all

very positive about the group and said they had been learning a lot about how to interact with their children and how to teach others to interact with them.

Thursday, November 29 (8:00am-2:00pm)

I spent my final day of the practicum at Sisizakele. First thing in the morning I had a conversation with Ms. Jood, primarily about the schools curriculum. She explained how kids were assessed and how they were able to progress through the grade levels offered by the school. The schools grade levels will progress as the children do, so when the level 4 students are all ready to move on, they will begin the level 5 curriculum. The conversation really helped me get a better idea of how the academic work was planned for at the school. I spent the rest of the morning working on my painting project. It turned out wonderful, and Ms. Jood was very pleased with the final product. After I completed that project I got to spend some time with the kids just playing outside.

After lunch I spent the rest of the day finishing the library cataloging project. Ms. Jood purchased some dot stickers for me to use to label all of the books. So I got all of the books in order and on a shelf that could be easily accessed by the kids. I am really hoping that starting at the beginning of this year, the teachers will urge the students who are able to really use the library and make reading a priority. Literacy is certainly one of the most important things for the kids to master if they are going to grow up to be productive citizens.

**Total Hours: 103**