

## **Challenges faced by Lindokuhle and other disabled children at Vukuhambe Special Schools Resource Centre (SSRC) in East London, Amathole District Municipality-Eastern Cape.**

**By Nondumiso Mtshayeni (Parent of Lindokuhle and member of Parent Support Group for Parents with Disabled Children in East London)**

### **Lindokuhle, 12 year old girl in grade 2**

Lindokuhle, is a 12 year old girl who has cerebral palsy with athetosis. She has been at a special school for learners with physical disabilities since January 2008. **However** she has not benefited from the school mainly because of the lack of therapists at the school, especially suitably trained speech therapists with a special qualification in Augmentative and Alternative Communication (AAC). She therefore has been deprived of her right and opportunity to education in spite of Rehab having facilitated the provision of all necessary assistive devices and programmes she needs for learning and communication.

### **1. Background information: Educational history**

- In **November 2007** Lindokuhle was **assessed** in Pretoria at the Centre for Augmentative and Alternative Communication (CAAC). Rehab was instrumental in facilitating this assessment - Reports from CAAC available on request. I quote from their September 2010 report:

**“After a detailed consultation and assessment of her abilities and limitations, Lindokuhle was found to be an excellent candidate for AAC. Specific recommendations were made, amongst which the acquisition of a laptop with the Grid Software Program as a way for her to start expressing herself and also get access to a computer which she would need in order to learn literacy and also to access the curriculum. An ETRAN (eye transfer communication system) was also recommended (low tech device).”**

The implementation of this programme would teach Lindokuhle to communicate and would enable her to start to learn to read and write (using a computer).

- At the beginning of **2008** Lindokuhle was admitted to Vukuhambe School but has not made any progress at this school.
- Being Lindokuhle’s mother I am very worried about my child’s lack of schooling. I have made every effort to promote the education for my child. I have been in constant contact with the school, the Education Dept, Rehab and private therapists. I have been relying on the Dept of Education for five (5) years now since Lindo was admitted at her current school, but unfortunately my efforts have not had any results as my child is still not receiving appropriate education.

## **2. Recommendation for placement at an appropriate school**

- As mentioned above, Lindo has encountered 5 years of **barriers** in terms of her right to basic schooling/learning. In a letter received from CAAC in September 2010, they write:

**“We were also made aware from a variety of people of the grave challenges Lindo faced, especially with regard to schooling. It seemed that she faced barriers in terms of educational practices at the school, such as over-burdened teachers who do not have background knowledge of, or training in the use of AAC and who are not able to give individual attention to her educational needs, as well as lack of AAC resources at school. We strongly recommended an alternative placement for her, ....”**

Up to now, the system has failed Lindo in several ways including:

- **her right to education,**
- **her right to communicate**
- **and her right to adequate care.**

With the situation as it stands including all I have gone through with regards Lindo’s education, I have all the reasons to believe that this is the violation of human rights.

As a parent, for the past four years, I have done the best I could do to get the current school addressed by the school and the department with no success.

- I strongly support the above recommendations of the CAAC and urge the Dept of Education to place Lindokuhle at an appropriate school, even if it means sending her to another part of the Eastern Cape, where schools are better resourced than the East London schools.

## **Challenges faced by Sibabalwe and other disabled children in Special Schools and Mainstream Schools in East London, Amathole District Municipality-Eastern Cape.**

**By Zoleka Mkhunqwana (Parent of Sibabalwe and member of Parent Support Group for Parents with Disabled Children in East London)**

### **Sibabalwe, 15 year old girl in grade 5**

Sibabalwe was diagnosed as Cerebral Palsy with athetosis a few months after she was born. She started at Vukuhambe special school resource centre in 2007. When she started at school, I took it to myself to attend school with her the whole year as no one at school could communicate or understand her. I was then available to assist the teachers and care givers not only with Sibabalwe but every other child that I could help with. It was unfortunate that I had to stop assisting at school due to the fact that I was often not welcomed by some of the teachers being in class during the lessons. Amongst other challenges at Vukuhambe, lack of therapists like speech therapists, social workers and professional nurses remains the main challenge affecting children with communication problems as Sibabalwe.

Both Lindo and Sibabalwe are were identified as candidates for CAAC program and the challenges that Lindo is going through are the same as experienced by Sibabalwe.

It is on the basis of this together with the two report tabled on Lindo and Kayla that we see the following critical issues as needing urgent attention in order to save the future of disabled learners in the Eastern Cape;

### **Critical issues for consideration with specific to Vukuhambe Special School Resource Centre in Mdantsane-Eastern Cape Province**

**Though highlighted in a special report on Vukuhambe, submitted to the Department of Education, 2009, no follow up has been done yet on these issues and the situation remains the same at the school.**

1. Review of policies & Acts governing Special Schools (Point 2 on Vukuhambe Report, 2009)
2. Strengthen links between the District Curriculum section and Special Schools (point 3)
3. Conduct a knowledge and skills audit of all Special Schools (Educators & Non-educators) and conduct structured and relevant courses & workshops (point 5)
4. Recruitment of therapists, Social Workers and professional nurses need consideration with specific to Vukuhambe being a Special School Resource Centre (point 6)
5. Teacher Aides independently marking learner's scripts and teaching-while neither qualified nor employed for such duties (point 3 General School Management)
6. The school has no Assessment Committee nor does it have an Annual School Assessment Programme as prescribed by the National Protocol on Assessment-Gazette No. 29467 of 11 Dec 2006 (point 1 Curriculum management)
7. Learner Representative Council (LRC) not involved in decision making and not part of SGB (point 5 Learner Welfare)
8. Older learners do not get physiotherapy and do not get any subsidy on tuition (point 4&9 Learner Welfare)
9. Learners changed diapers only after 8 hours irrespective of whether they are incontinent or not including those having their menstrual periods (point 10,11&12 Learner Welfare)
10. Inclusion of disabled children in mainstream schools with necessary support by the schools and department (DBST)

**Annexures**

- Report on Vukhambe SSRC, October 2009. Department of Education Eastern Cape
- Grievances of Learners at Vukhambe. 25 April 2009.
- Observations by Occupational Therapist, Mostert, A. June 2009.

## **Challenges faced by Kayla as a disabled child within Mainstream School in East London, Amathole District Municipality-Eastern Cape.**

**By Nomakhwezi Gocina (Parent of a disabled child and co-ordinator of a Parent Support Group for Parents with Disabled Children in East London)**

### **Kayla: 11 year old girl in Grade 3**

#### **Background**

- **Kayla** is an 11 year old girl, diagnosed with Mosaic Down syndrome at birth. This condition has mainly affected Kayla's communication while she is able to do anything under the guidance of her parents at home like any other child. The fact that Kayla is unable to communicate clearly often requires patience and also needs another person to get to spend time with her in order to clearly understand her when expressing herself. This means co-operation between the school and parents for the sake of Kayla's progress at school. This has been the major challenge facing Kayla's parents since she started her Grade R in 2009.

**Current situation with school:** Kayla is in Grade 3 in a mainstream school. It's been a very challenging time for the parents with regards to Kayla's schooling especially the last term in 2011 when they were informed by the school and the department official that Kayla was not supposed to be in mainstream school. However, when the parents started working with Kayla's new teacher this year, things became promising as the school started involving them as the family in educating Kayla. They were determined that the problems that teachers apparently had with Kayla, could easily be addressed. The main concern that the parents had was the fact that the school was supposed to have contacted them as the family/parents of Kayla when they identified some challenges and not just take a decision to move Kayla to a special school.

The two school meetings on Kayla's progress at school were promising as the teacher seemed happy with Kayla's progress. However, the mother was again caught by surprise when the school called to inform her that a meeting was set up for her in a special school to discuss the possibility of admitting Kayla in that school. The speech therapist that is currently working with Kayla has contacted the school to understand the reason for moving Kayla to a special school and the response was that the school does not cater for children like Kayla. The school has now told the mother that the school will no longer admit Kayla next year.

*"I feel that they did not do anything for Kayla from day one on. Inclusive Education was never implemented. In Grade R everything was going well but in Grade 1 when Kayla did not cope she was not helped in any way. I do not remember a single day the teachers have approached me to tell me they have challenges and how I could assist them, but I was told that there are schools for people like Kayla and that a mainstream school is not for her. The department official from Inclusive Education who was in one of the meetings bluntly told me that inclusive education does not work in the Eastern Cape and there is nothing they can do but move Kayla to a special school. To be honest, I sometimes wonder if it's worth fighting or should I just take my child out of that school. To me she has wasted her time there in learning. I feel drained and as a parent I feel that I failed her." (Parent focus group, 2012).*

**The question remains**

Does this child stay at home because “Inclusive Education does not work in the Eastern Cape”, as the district official once said to the mother and also because her current school ‘does not cater for children like her”.

## **To whom it may concern**

### **Some observations made by Annegret Mostert, Occupational Therapist, regarding Vukuhambe School in Mdantsane, East London, June 2009**

#### **Introduction**

Vukuhambe School is one of the few schools in East London which provides special services and schooling for children with disabilities. It is potentially a great resource to children with disabilities and their parents. It also has boarding facilities without which some children with severe disability, from outlying areas, would not be able to attend this school and therefore would not be able to attend any school at all.

#### **Background Information**

I have been involved at Vukuhambe School since January 2009 when I was asked by a funder, who had donated wheelchairs to the school, to assist with fitting and seating the children in those wheelchairs. While working with the children and some staff members, I made the **observations** which are mentioned below. I will discuss them as follows:

- 1. Numbers and disability of learners**
- 2. Services at special schools**
- 3. Seating issues**
  - **Wheelchairs**
  - **Foot rests**
  - **Cushions**
  - **Wheelchair care**
- 4. Deformities and contractures**
  - **Spine**
  - **Ankle**
  - **Hip and knees**
- 5. Bladder and bowel training**
- 6. Pressure sores**
- 7. Computers**
- 8. Mainstream schooling for learners**

## Observations

### 1. Number and disability of learners (in March 2009)

- Total number of children at school: 188
- Number of children in wheelchairs: about 60
- Number of children in boarding facility: majority of children

Disability	Female	Male
Cerebral Palsy	49	55
Other physical disabilities	46	35
Epilepsy	3	
Intellectual impairment	?	?

### 2. Services at special schools

Many of children at this school are **not receiving the service and rehabilitation** which a special school like this should provide. It is an impossible task to provide these services without a team of rehabilitation workers. For the past 9 years one physiotherapy assistant had to try to see to the many rehabilitation needs of the children at this school. Poor services can have a detrimental effect on the children for the rest of their lives. This may result in the following:

- Their independence and general functioning is hampered.
- Social and sport activities are diminished.
- Lung capacity or other organ functions might be limited.
- Pressure sores can develop.
- Academic performance may be stifled.
- Their personal appearance is negatively affected.
- Contractures and other deformities can occur which may require expensive surgery at a later stage to correct the problem.

### 3. Seating Issues

- **Wheelchairs**

Many children are using **wheelchairs which are not suitable** for their specific needs, i.e. the chairs do not give sufficient postural support, or the children are **incorrectly seated**, e.g. the wheelchair is not adapted to their needs. **This is one of the main causes for spinal deformities.**



### Examples of seating problems



Figure 1: Wrong type of wheelchair and too wide



Figure 2: Wheelchair is too wide and no foot rests



Figure 3: Wheelchair is too small



Figure 4: Cushion not used, not provided or has disappeared

- **Footrests**

Foot rests are an important part of the wheelchair and of seating because of the weight distribution through the legs. Some foot rests disappear without reason. Some footrests are on the chairs but don't serve their purpose because the feet cannot be positioned on the footrests for a number of reasons.



Figure 7: Foot rests missing



Figure 8: Foot rests not used because of incorrect seating

- **Cushions**

**Cushions are crucial for correct seating, postural support and prevention of pressure sores.** They are often not used, in spite of being specifically issued and adapted for individual children. At times children sit on wet and smelly cushions, or leave their cushions in the dormitories.

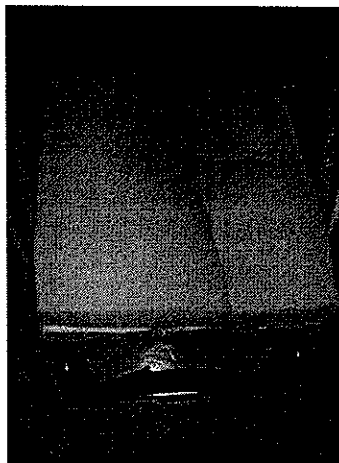


Figure 5: Wet and smelly cushion

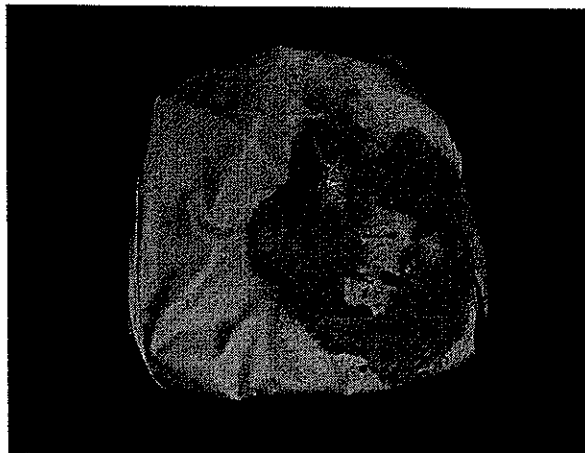


Figure 6: Wet cushion cover

- **Wheelchair care**

Wheelchairs and cushions are not labelled and are at times used or damaged by other children.

Some showers are not equipped with special shower seats or are not accessible, and therefore children have to shower in their wheelchairs. This practice severely damages the wheelchairs.

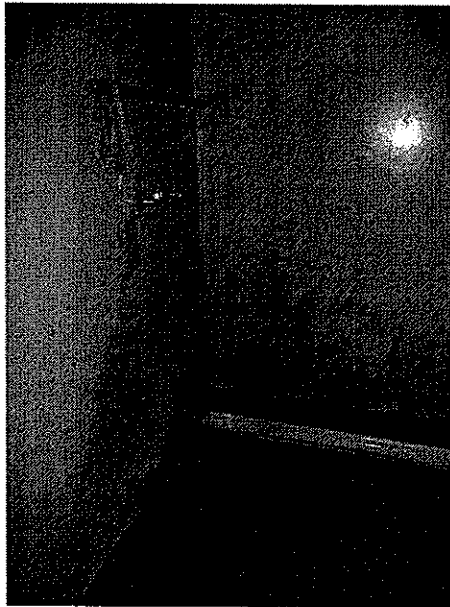


Figure 9: Not enough shower seats

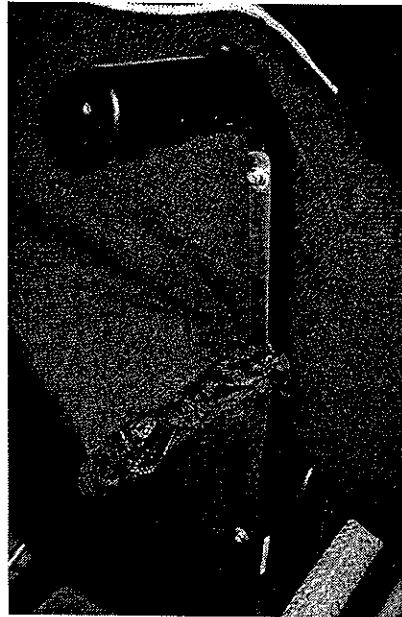


Fig 10: Broken wheelchair

#### 4. Deformities and contractures

- **Spinal deformities:** The majority of the children in wheelchairs at this school have spinal deformities; some have severe deformities.

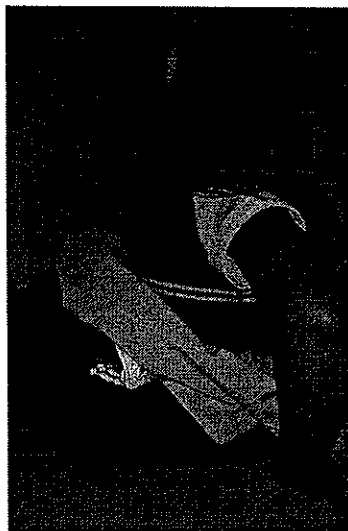


Figure 11: Spinal deformity

- **Ankle deformities**

Most children with Spina bifida have stiff ankles (pointed feet), and therefore cannot wear shoes or weight-bear on their feet, i.e. cannot stand in a standing frame or with callipers.



Figure 12: Ankle deformities



- **Knee and hip problems**



Figure 13: Knee contracture



Figure 14: Hip contracture



Figure 15: Hip dislocation

#### 4. Bladder and bowel training

Many of the wheelchair users are in nappies, in spite of the fact that some of them could be toilet trained or trained in bladder and bowel management (e.g. children with Spina Bifida).

In May 2009 nappies were not available at the school for more than a week and some children were sitting on wet and smelly cushions and in wet clothes (this could cause pressure sores).

Some intermittent catheters are kept in pockets or held in the user's hand (not in a sterile container). There is a concern that this practice could cause bladder infections.

Some children are wet in spite of intermittent catheterisation.

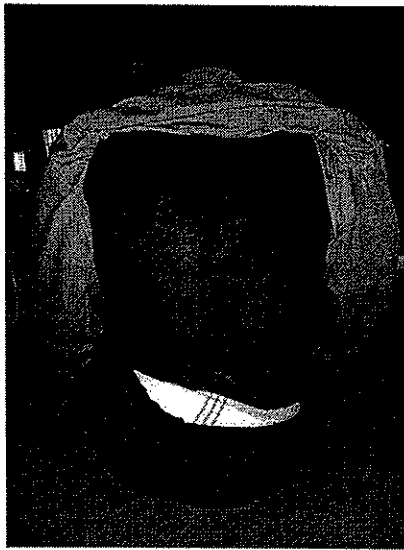


Figure 16: Big children in nappies

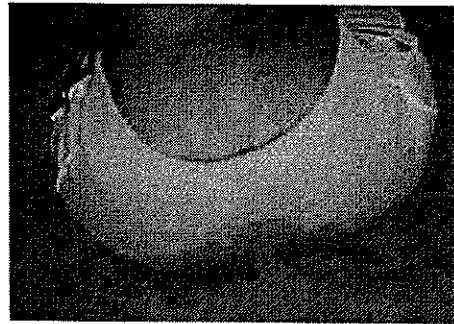


Figure 17: Wet trousers (nappy shortage)

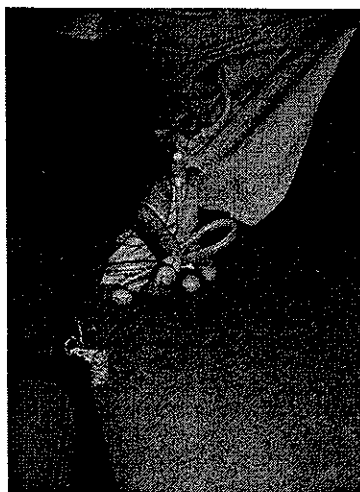


Figure 18: Catheter not sterile

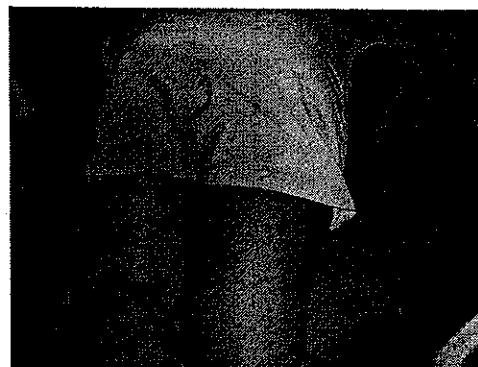


Figure 19: Wet clothes in spite of catheterisation

## 5. Pressure sores

There is evidence of pressure sores, which have not been healed over a long period.

Some children's pressure sores worsen during school holidays, partly because of lack of knowledge and dressing materials which could be provided by the school.



Figure 20: Pressure sores

## 6. Computers

The school has 2 well equipped computer labs, where all learners go for specific periods. There are however some learners with severe disabilities who are dependent on a computer but who are not allowed the use of a computer in their classrooms, thus excluding them from participating fully during the lessons.

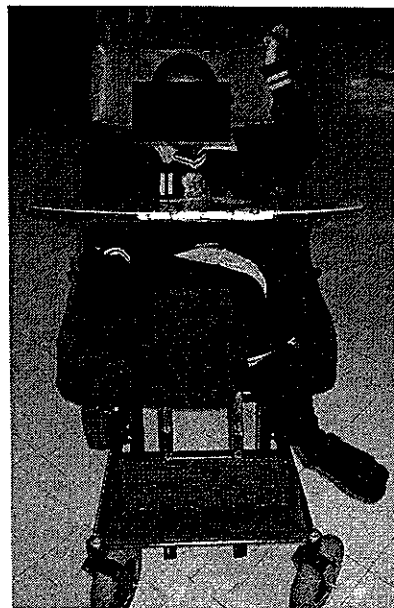


Figure 21: Children with uncontrolled movements are dependent on computers for communication and learning

## **7. Mainstream schooling for learners**

It is noted that children who would be able to cope in a mainstream school are attending the special school, (i.e. children with normal intellect and minimal physical disability), in spite of the Department of Education's policy on inclusive education.

## **Conclusion**

Vukuhambe School is a valuable resource in the East London area for children who have special needs. These needs have to be addressed in a satisfactory manner in order to promote the wellbeing and maximum level of functioning of each learner. If this does not happen, the children's lives are negatively affected and they will not be given the opportunity to become independent and contributing members of society, but will become a burden to society. At the present moment Vukuhambe School does not provide all the necessary services for children with disabilities. These children, who are already coping with a disability, have the right for better services.

A multidisciplinary approach is required to support the education system at this school i.e. doctors, nurses, social workers, occupational, physio and speech therapists. A team like this, coordinated by the school management and supported by the entire school and hostel staff, would be able to implement the following:

- An efficient rehabilitation regime to minimise the above mentioned problems
- Prevention, treatment and management of pressure sores
- Bladder and bowel training and toilet training programmes
- Counselling of children and their parents when needed.
- Medical care and counselling.
- Appropriate screening for admission to the school.

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June 2009