

Case Study on a child with a chronic illness

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DICAG 13 August 2004

Introduction

My name is Nonceba Meyiwa. I am a parent of a child with a disability, and a member of the Disabled Children's Action Group. I stay in Duduza township in Nigel, which is in Gauteng. I am an active member of my community, and people frequently come to me for advice and help.

I would like to talk to you today about a situation that has arisen in our community. It is about a boy aged 14 who has a psychiatric illness. It illustrates many of the problems facing children with disabilities and chronic illnesses in our communities – and reminds us particularly of the difficulties of children with “invisible” disabilities, and not just those with physical disabilities. I believe that this is not an isolated case, but a situation that is frequently encountered in many of our communities. Consideration of this child's situation will inform us as we discuss issues around the Children's Bill, as it will remind us of children that are most vulnerable, and who need to be protected and provided for. It will also show us clearly where the gaps and problems with the present system are!

The story of Sifiso

Dudu was a mother of three children. Each of them had a different father, and none of these fathers were living with the family. Dudu and her children stayed at Extension 3, Duduza which is a township in Nigel in Gauteng. They were living in a “RDP house”, which is the low-cost housing built by the government. The house is one big room, which is un-partitioned and unplastered.

At the beginning of 2003, Dudu brought in a boyfriend to stay with the family. The boyfriend left after Sifiso chased him away, after repeated constant fights, because the boyfriend was not his father. Dudu got ill as a result of AIDS, and she died early in 2003. The three children were left alone in the house. At the time of her death, all three of them were attending school. Sifiso was in Grade 6, Andile in Grade 5 and Nomathemba in Grade 9. After the death of their mother, the children were helped by a neighbour who gave them food and offered supervision. Nomathemba worked at Coal Trance in Nigel at weekends, so as to help to buy food and pay school fees.

Soon after the death of his mother, Sifiso, who was 14 years old, began to show strange behaviour, and stopped attending school. He engaged in drugs. One night at about 2pm he smashed all the windows of the house. The other children screamed, calling to the neighbour Pinkie for help. She took them into her house. At the time, Sifiso was threatening to kill anyone who got near him. He said “What I have done is nothing – greater things are still coming.”

In the morning, Pinkie woke the children to prepare for school. When they got back into the house, they found the electric stove red, having been lit by Sifiso for the whole night.

Since Sifiso was no longer attending school, the principal reported the incident to local social workers. The neighbours wanted to discipline Sifiso, thinking that his “naughty” behaviour could be corrected by hitting him. This shows the dangers to which such children are exposed

Then Sifiso, for no reason at all, burnt their home. Then he would close up the windows with cardboard boxes, and the burnt house became “home” for 20-30 street children, or children who had run away from home. Some as young as 8 years old. The neighbours would report the kids to the police, and when the police came, the kids would escape through the windows, scattering through the neighbours premises. The police would apprehend some and return them to their homes. But by evening, many of them would be back. *Yesterday we heard about the need to solve the problems at home, before taking the children back there.*

When all this was happening, Sifiso’s brother and sister continued to stay with their neighbour. Nomathemba, who was concerned about her brother, took him to St John’s church, for healing. This is a church in the location. At the church, they would keep him tied up for the whole day, so that he would not run away. However, they got tired of him because his condition was not improving, so they told his sister to leave school, and come and look after him 24 hours a day, as they could not offer that service any more. They initially wanted her to go to St Johns to look after him there. Pinkie, the neighbour, advised her against doing so. So the church released Sifiso, to be cared for by his sister and brother (other children), with no ongoing support.

The social workers offered help to Andile (the youngest child) who has been placed in a children’s home. Pinkie the neighbour says that he looks well, and he visits her, and helps her with different tasks – like in the garden at her home. Nomathemba is at school doing Matric, and working on weekends. She is staying with a friend, and has engaged in the adult life of men! The neighbours suspect that she is using this as an additional source of income.

Right now, Sifiso’s whereabouts are not clear. He is not at school, and he is not in the location. We are not sure even where he is sleeping. Some people said that they have seen him in the streets at Sharon Park, which is a suburb between the location and Springs. This is really a child in very difficult circumstances.

Issues that it raises for the Children's Bill

Children in need of care and protection

The Children's Bill makes provision for children in need of care and protection. If the social workers had been informed earlier, and if the problem had been identified earlier with the help of the community, perhaps this damage would not have been done. It was not until the school picked it up – and after the damage had been done – that the social workers were involved.

Child headed households

This story again reminds us that CHH are a reality. We have an illustration of how mentorship happened when the neighbour offered help. But this was an informal arrangement. There are many such cases of informal mentorship by neighbours of children in difficult situations, which could be one mechanism for providing support to the children. The Dept of Social Dev needs to look into these mentorships, and to ask how they can be supported, and how they can be monitored. For example, Pinkie has a drinking problem, which may have a detrimental effect on her ability to provide care for these children. There is the danger that mentors could further abuse the children.

Facilities

Sifiso is a child with a psychiatric illness. When he is acutely ill, he needs to be treated at an in-patient institution, with follow-up by community mental health services. However, the closest facility to Nigel is in Johannesburg, which would mean 3 consecutive taxi rides.

Child psychiatric in-patient services are currently available at Weskoppies, Tara and Witkoppen, in the Gauteng Metro, and at Cullinan Care in Pretoria. The child unit at Sterkfontein has closed down. There are a number of clinics which offer weekly mental health services, and most of these are serviced by a psychiatric nurse, who is available for consultation.

This shows that there are very few institutions offering psychiatric care for children. Even the informal day care centres started by many of our parents to cater for their children with disabilities, cannot offer such a child support. This is very worrying, considering the prevalence of psychiatric disorders in South African children, which is estimated to be around 14% - 20% (SAHRC Report 2002 *Towards a barrier-free society*)

Involvement of different sectors

Schools are one of the mechanisms for early identification of children in difficult circumstances. In this case, it was the school principal who called in the Social Workers when he noticed that there was a problem. These children were in contact with SAPS when the major incidents happened. Neighbours called the police when all the children were gathered in the house. But they never asked *why* this was happening, and what the cause of the problem was.

Because his condition fluctuates, it is essential that Sifiso – when he is found - receives on-going medical care, so that it can be controlled. Unless long-term monitoring and follow-up is done by the Dept of Health, he may manifest further episodes of violent and destructive behaviour.

Ownership of property

How will these children be assured of continued ownership of the property (their home), and do the necessary repairs to it?

This child has not been helped, wherever he is. Instead people wanted to “hit” him, or send him to St Johns for help. The danger is that, given his chronic condition, some factors may again trigger his aggressive and violent behaviour, which may result in serious damage or injury, even leading him into trouble with the law. But this is a child that needs treatment, protection and support, not punishment.