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Robbed of Dorothy!

The Painful Realities of HIV/AIDS in an Organisation

Betsy Mboizi (CDRN) with
Rick James (INTRAC)

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INTRAC
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The Painful Realities of HIV/AIDS in an Organisation

Betsy Mboizi with Rick James

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In our hearts, I suppose, we thought we were immune from the impact of HIV/AIDS in our organisation. The problem was 'out there'. We were really living in organisational denial. Yet as a provider of capacity building services, we (CDRN Community Development Resource Network in Uganda) had put more effort than most into mainstreaming HIV/AIDS into our organisation – just in case. We even had an HIV/AIDS policy that we hoped would protect us from the worst impact of the disease. This last year has shown us in very painful ways how naïve we were.

This is the story of how Dorothy, one of our staff members, became sick and passed away. It is a story that is becoming all too familiar in Africa. We share it in the hope that the story of Dorothy's death provokes you to realise that AIDS can happen to your organisation; that it does help to be prepared; and yet however prepared you are, AIDS in the organisation is so painful and costly that it shakes you to the core and challenges your very values.

Dorothy's Best Days

Dorothy joined CDRN in November 1999 as a secretary – one of the rare breed of people who move from an international NGO (Concern Worldwide) to a local NGO. A methodical, but not high-flying worker, she later was promoted to administrative assistant due to her good computer skills. These skills were further honed by a computer studies course and then broadened by a course in Social Worker Social Administration. Staff remember Dorothy as 'happily occupying the front desk like a driver who had just passed a driving test, seated steadily, ready to drive the bus to its destination'. She was a humble person who worked at her own pace and cautiously ventured into new areas in her work. Socially she was a likable and dependable person. In the words of one staff member: 'Dorothy was a warm person…who was always willing to assist'. She was 'young, energetic, brown and beautiful, whose face was ever full of smiles' according to another. Dorothy was the 'face of CDRN who treated both outsiders and insiders with passion'.

When Dorothy arrived at CDRN she was a young widow with two children. She had separated from her late first husband six years earlier having been badly mistreated. She then remarried and her new husband was studying abroad with Dorothy's support for part of his school fees and up-keep. Although Dorothy was only third-born in her family, because she had a job she acted like the first born, supporting her family financially. She also paid school fees for her younger brothers

and sisters and looked after the relatives of her second husband. When her husband returned home Dorothy introduced him to the staff with evident pride. Soon she became pregnant again and gave birth to a baby girl named Cynthia. At CDRN we were overjoyed with the news.

But in 2002, Dorothy started to complain about feeling unwell due to lack of sleep and overworking at the office. Her performance at work started to deteriorate and from being a young energetic woman she became a sickly and depressed colleague. She found it increasingly difficult to climb the stairs to the filing room. Staff thought, 'No this can not be true, she is too young and strong hearted. She will pull through. This will not take long and she will be up and running.' But she got worse and was admitted to hospital for two weeks.

When she returned to work her diet had changed and she was eating lots of fruits and less oily foods. Her sickness started affecting us more when her morale deteriorated; she lost interest in jokes and was always in pain. We provided lots of sympathy, giving her less work and reducing our expectations of her outputs. She started exhibiting signs of depression and was complaining of headaches and an inability to walk. She would fail to come to work on particular days. I knew there was something fundamentally wrong. But what should we do?

If you were her manager, what would you do?

I suggested to her privately that she would greatly benefit from talking to counsellor. She discussed the idea with the finance department and funds were made available. She improved a bit and was happy with the counsellor. But at this stage her second husband deserted her, leaving her to care for the children alone.

CDRN's Policy Response to HIV/AIDS

Fortunately, CDRN had realised the year before that we needed to do more internally to adjust to the HIV pandemic in Uganda. Previously we had been wary of being sucked into becoming an HIV/AIDS capacity building organisation and had chosen to leave HIV work to others. After all, CDRN could not do everything. We made many excuses from 'lack of skills', 'limited human capacity', 'we are not a health organisation', and 'we are not operational but capacity builders'…Now I can say we were in a state of denial.

Two main factors brought a change to CDRN. First, one of our main donors, CORDAID, had entered into a long-term relationship with us and one of the key objectives was about helping CORDAID partners with HIV/AIDS and health issues. Second, and at about the same time Sarah, the woman who cooked at the CDRN offices (and who used to work in the Director's house) was starting to get sick on and off. Her husband and one-year-old child had died. She confided in our Director about her sero status, but as a casual labourer had little option but to carry on working. She had medicines to take, but her condition worsened and she was sick for months before she died. All the time the Director was quietly paying hospital bills, finding the right doctors and supporting her children. This personal experience did much to convince the Director and CDRN staff that we should start thinking and doing more about HIV/AIDS both with our partners and ourselves.

With CORDAID support we developed a health policy to support prevention, care and mitigation of the effects of HIV/AIDS. Through update meetings and workshops the capacity of staff was built to increase awareness, sensitivity and the ability to cope with HIV in our midst.

The health policy covered issues of:

- ✓ Non-discrimination in recruitment of staff;
- ✓ Preventive measures to avoid staff contracting the virus;
- ✓ Flexible working conditions for sick staff;
- ✓ Sick leave and leave for care-givers;
- ✓ Leave provisions for staff with long-term illnesses;
- ✓ Counselling services: CDRN pays for VCT (Voluntary Counselling and Testing);
- ✓ General support such as a non-stigmatised environment;
- ✓ Medical cost sharing (CDRN contributes 75% of ARV Anti-Retroviral costs, all staff contribute 1% of their salary to the scheme);
- ✓ Special development scheme for dependants and survivors;
- ✓ Will writing so that survivors did not suffer from property grabbing;
- ✓ Retirement on grounds of ill health or voluntarily;
- ✓ CDRN funeral responsibilities in case of death of staff member

Difficult and Distressing Times

CDRN's mainstreaming efforts did much to ensure ongoing emotional and financial support for Dorothy, whose health was clearly deteriorating. In February 2004 we employed a Relief Administrative Assistant to lighten her work load. The next month Dorothy fell ill again and this time was mentally very disturbed. One staff member recounts the story: 'We got a phone call from the family members saying Dorothy had gone mad. We were all puzzled. Proscovia (the Finance and Administration Manager) suspended all office work she was handling and asked the head driver to get a vehicle and some colleagues to go now to rescue Dorothy. The car sped to Dorothy's rented house and found Dorothy's children, relatives and friends all standing aside in fear of their lives. Dorothy was behaving like a mad person. As we reached we were not spared either by her. She started spitting on our faces like a puff adder attacking its enemies in self-defence. When we confronted her she put up a very hard fight and only after a long struggle did we manage to control her and get her to hospital'. As staff we all supported her through frequent visits and paid all hospital expenses. We spent a lot of time comforting the family.

Eventually Dorothy was discharged and returned to work. She started going to a Pentecostal church for prayer and counselling. While this provided important psychological and spiritual support, the church discouraged her from taking ARVs and she stopped. What could we as her employer do? How private was Dorothy's 'private life'? At the office Dorothy would not talk about her illness, even when she started frequenting the outpatient clinic at the hospital where CDRN staff are insured. When Dorothy came to work she would complain bitterly. 'Now my stomach is paining me. I have wounds in my mouth. My legs are all swollen. I have no appetite. I cannot eat and even walk. All this is too much for one person to bear!' Yet the next day she would reassure us that she was getting better. Many times when I talked to her she referred to the symptoms and not the cause. She would also say that investigations are ongoing. I felt very let down because I have counselling skills with a medical background which I was failing to put to use. The Church approach might have been comforting, but was not medically appropriate. We desperately wanted to do more, but what?

If you were her manager and she refused to be open, what would you have done? What would you have done when she stopped taking ARVs?

What role do you have in the spiritual and medical lives of your staff?

To show that we had not given up on her, to keep her from losing hope and also to challenge her denial of her condition, we even sent her on a training course on Women and HIV/AIDS in Zambia in June 2004. She never even had a chance to feed back from this training.

Once Dorothy stopped taking the ARVs, her condition quickly deteriorated and she was soon admitted to hospital again. This time she was in intensive care for more than a month. The hospital was near the CDRN offices which made it easy for staff to visit her frequently and meet financial demands.

Supporting Dorothy through her illness was taking its toll on CDRN. We were bending over backwards to provide appropriate support and care. But we had no choice. What else could we do? CDRN is a values-driven organisation and how could we talk about caring for the poor in the community if we did not even have the love to practise it in our organisation? We were paying a high organisational, financial and emotional cost.

In organisational terms:

- Dorothy's performance at work was declining and several important files were misplaced.
- We tried to make work less strenuous for her and allowed her to work as long as she felt able.
- She was granted six months sick leave with full pay and full benefits. This was far beyond the three months stipulated in the policy – but as a close colleague we knew how much her family depended on her.
- When she stopped working, we lost part of our organisational memory. As one staff member said: 'We dance around these days because of the lack of IT knowledge that she had'.

Financially CDRN covered significant costs (see Box 1):

- We paid for her counselling and provided necessary transport to and from hospital whenever it was needed.
- Dorothy was able to access ARVs through our medical insurance, though CDRN had to chase up all her insurance moneys as per policy obligations.
- The staff welfare fund supported by monthly contributions from staff and CDRN was completely drained, leaving other staff frustrated with nothing left to pay for the sicknesses or funerals of their own relatives.

But these financial costs were not as high as the emotional cost to staff morale:

- Dorothy's sickness made the whole organisation depressed. For months, there was a black cloud over staff meetings where her health was regularly a key agenda item.
- We spent considerable personal and organisational time visiting her in the hospital and made personal and collective contributions to her in form of money and gifts.
- It was very psychologically draining on all of us. Staff relate how they endured watching her mother 'seated by her bed-side wiping her tears as she saw her daughter being taken into the world of the dead'. They saw 'her baby Cynthia crying mercilessly as if she knew she was about to miss her mother's warmth and care forever. Her other children watched helplessly on. Dorothy's brothers and sisters gathered round her as if to shield her from the enemy but in vain.'

Seeing no hope in the hospital Dorothy asked to be taken home. In October 2004 she died – while we were travelling back from an INTRAC Praxis event. We had lost a dear, if sometimes difficult, member of our family. CDRN took care of all funeral expenses such as the coffin, feeding all the guests, flowers, and transport up to her home village in Shironko. We closed down for the day and many staff travelled to the funeral. The pain of watching her young son lay a wreath of flowers on the coffin reminded us of how her death would affect her own family. The speeches revealed again what a central role she had played in supporting them, even after her husband disappeared from the scene.

The Financial Implications for CDRN

CDRN paid a very heavy price for our commitment to Dorothy and to mainstreaming HIV/AIDS in our organisation. But in moral terms did we have a choice?

What would you have done while still being true to your core values?

Although the financial costs to CDRN were not as high as the emotional costs, it is instructive to see how much we spent on Dorothy (see Box 1).

At CDRN we were in the fortunate position of having the freedom to use our own money to pay for these costs (we earn about 30% of our income from fees). What about other NGOs tied to restricted donor budgets? It is not so easy for them. Their donors understandably want their limited resources directed to helping the poor in the communities, not spent on 'overheads'.

Box 1 – The Cost of Caring

- Transport for medical appointments and hospitalisation US $450
- Hospital bills of US $3,315 for all her admissions
- Mary was employed as temporary cover to lighten Dorothy's workload for nine months. This cost a total of US $2250
- Funeral expenses of US $555
- Staff spent about 3 days each on issues related to Dorothy's illness – calculated at US $3392

This amounts to US $9962, 210% of Dorothy's annual salary or almost **4% of CDRN's annual salary bill.**

The Importance and Limitations of Policy

It is all too easy for an organisation to bury its head in the sand and pretend that HIV will never affect them. We thought it would never happen to us. This organisational denial is so dangerous. It prevents the organisation from thinking strategically and preparing for an almost inevitable issue. When you look at the statistics in sub-Saharan Africa, having an employee infected with HIV is only a matter of time. It is not a question of if, but when. Sooner or later you too will have your own Dorothy.

It certainly was extremely helpful for CDRN to have developed an HIV/AIDS policy. It gave us guidelines to follow. The process of developing the policy had made staff very aware of the issues as well as the need to support and not stigmatise HIV+ staff. Without such a policy we would not have known how to respond and even more time would have been spent agonising over what to do. Staff

morale might have plummeted even more if CDRN had hesitated and appeared cold and blind to our employees' suffering.

Dorothy's experience showed us both the value and limitations of having a health policy covering HIV/AIDS. The policy was a necessary, but not sufficient, response. While our policy looked so nice and rosy on paper, implementation proved traumatic. Our feminine caring culture came to the fore at a time of internal crisis. Because Dorothy was a friend and colleague, not just a human resource, we went far beyond our stated policy to help her. We felt we had to live out our stated CDRN values of standing with the most poor and marginalised – an abandoned HIV+ woman with three children to support. If we had followed the policy guidelines to the letter, we would have compromised the core values that made CDRN what it was.

If you were her manager, what would you have done in our situation? What would you have done when her three months paid sick leave was up? Could you really follow her husband's example of abandoning her?

For better or worse, we felt that ultimately policies are inanimate procedures designed to give sensible guidance – but in the face of a dying colleague must be over-ridden in order to maintain our humanity. As Africans we believe organisations are much more than just structures and systems. They are a web of human relationships that create communities at work. We believe in the concept of *Ubuntu* – that 'I am because we are'. We wanted to maintain the friendliness and warmth of CDRN's culture. We felt the values of compassion that underpin our work in the field had to be consistent with our practice in the office.

Difficult Dilemmas

The experience of Dorothy's death from AIDS has left CDRN with more questions than answers:

- Can we respond in the same way for others in the future?
- Have we set a precedent which will prove impossible to follow?
- What about other CSOs who do not have the luxury of untied income to spend on staff welfare?
- Should we have done more to prevent her getting infected in the first place?
- What should we be doing for other staff today?
- Is an employee's private life really private?
- What should we do if we know an employee is 'running around' and not protecting themselves? Is it any of our business?

One thing we are sure of. While we do need to be as prepared as possible, when HIV hits us again it will be excruciatingly painful. No amount of preparation, no policy can insulate us from this pain and retain our compassion. What really hurts us about Dorothy is certainly not the $10,000 CDRN spent. No, we mourn the loss of a friend, a colleague; the loss of a young mother; the loss of a life full of potential and dreams. We must do all we can to prevent anything like this happening to our staff again.

What are you doing about HIV/AIDS in your organisation?

What are you doing to help the organisations you work with?