

6. Appendix 1: Statement of ethics

As participatory researchers with children we will:

- respect the rights of children as provided in the United Nations Convention on the Rights of the Child;
- ensure that the research is conducted in a way that benefits children's physical, psychological and social development;
- encourage children to speak, and listen to them;
- ask for informed consent of children, and their parents where appropriate, before involving them in research or in disseminating research information;
- honour children's priorities and interests;
- honour children's cultural values;
- treat children as adequate and capable social actors;
- not impose the researcher or the researcher's ideas on children;
- not use any form of abuse or exploitation for research purposes;
- not put children at risk for research purposes;
- not hide information from children;
- not discriminate against children on the basis of age, gender, socio-economic status, caste, religion, language, race, ethnicity, capacity;
- where appropriate, try to involve children in conducting the research;
- ensure research report ownership by children or where appropriate their parents or other related persons;
- not use material without the informed consent from the participants;
- not give out real names of persons or organisations without informed consent; confidentiality of all sources will be maintained;
- not use material that will be threatening to the children, even if they have given their informed consent;
- give appropriate weight and value to children's feelings;
- disseminate findings to the group(s) that contributed to the research, in media that they can understand;
- give materials gathered from research participants back to the participants, keeping copies only with their informed consent.

Adapted from a declaration during a course for researchers in participatory research with children in India/Nepal in 1995, as recorded in Boyden, J and Ennew, J (1997).

5. References

Boyden J. and Ennew J. (Eds.) 1997, *Children in Focus; A Manual for Participatory Research With Children*. Stockholm: Rädda Barnen

Bronfenbrenner, U., 1979. *The ecology of human development. Experiments by nature and design*. Harvard University Press, Cambridge MA.

Bronfenbrenner, U., 1986. Ecology of the family as a context for human development: Research perspectives. *Developmental Psychology*, 22, 732-742.

Dawes A. 2000, What happens to children when they participate? Moral and social development, *Children's Participation in Community Settings*. Oslo: ChildWatch International.

Ivan-Smith E. and Johnson V. 1998, The Way Forward. In E. Ivan-Smith and V. Johnson (Eds.), *Stepping Forward: Children and young people's participation in the development process*. London: Intermediate Technology Publications.

Kjørholt AT and Qvortrup J, 2000, Children's participation in social and political change - Western Europe. In *Children's Participation in Community Settings*, Childwatch International Research Symposium: University of Oslo.

Analysis

What is striking about this case is the systematic approach that this principal has developed. Intuitively she has applied an ecosystemic approach (Bronfenbrenner, 1979, 1986), which is based on the idea that a school is not isolated from a community but both are part of the same system. Her response is an excellent example of schooling that takes into account the context in which the children are learning.

The programme she has developed responds to the developmental needs of the children in her care in a holistic way. There is a feeding scheme, a project to meet psycho-social needs, a project to address the home situation and a project that looks at children's cognitive needs and need for recreation.

The fact that the principal feels overwhelmed by what she has taken on is significant. The case study points perhaps to the reason why more principals and teachers do not respond – once you open yourself to the need, it is so vast that it overwhelms you. The principal makes an important point about the need for all government officials in an area to work together. She is clear that if this were the case her job would not be so overwhelming.

I even make sure we have money for trips for sport for the children. I never turn a child away who cannot pay. Only those who can, pay fees.

Uniforms

For uniforms we have a plan too. We get second-hand uniforms and parents wash and mend them and we give to those who cannot afford. We also collect other clothes for children. Teachers bring clothes and when we go on holiday we always say bring old clothes back for us. Also the local church helps me a lot with old clothes.

Emotional support

I have a project now to do something about emotional support for these children. I have someone from the local university who is coming in to train peer counsellors. We are starting with the teachers who are going for a week of training. Then we will select children from each class from as young as Grade 4 to train them to be peer counsellors. We are not saying they should do everything but they can watch and direct children to other help if they need it. It is also teaching children to support each other when things are bad. I give a lot of support like that. After hours my office is always open.

I also make sure the children do sport and cultural activities. These things are where they can be themselves. Once a week we have a sport day from 12.00 and everyone plays sport even the Grade 1s. We have our own soccer team that meets at the school. We even have a girl playing in it. It is young children from the school but they are part of the league.

We also have a culture day once a week from 12.00. We have dancing and debates. Everyone participates, the little ones read from books and the big ones debate. This makes school interesting for them and this is important for children who have problems at home. They will stop coming to school if it is not interesting.

A model for other schools?

I often think that it is a big task to do something like this. Once you begin to look at the need it just grows and grows and sometimes I feel overwhelmed. I think that other principals could do it though. The main thing for me is that if other government departments in my area were doing their job properly it would not be such a burden for me. I could refer children to get grants and the clinic could help with sick parents. I love doing what I am doing but I need assistance. I don't need people to tell a child to bring their mother to the clinic in a wheelbarrow! I need them to care a bit and come to the aid of children. If all the different departments pulled together it would be better, we could cope.

The main thing for me is the children. We need to do these things so they can learn. It is our job as a principal. They have so much potential – they deserve this – it is nothing special, it is what they deserve.

food parcel. But the problem is then people need paraffin to cook and the food does not last. So last year I started a project to get Child support grants for all the little children who are linked to children in the school. But grants are such a struggle. We have registered as many children as possible. But the big problem is Home Affairs and birth certificates. These families do not have certificates. They are not literate people or educated and it is so difficult. The other problem is that they may have a grant for some children in the house but now so many people are sick they cannot get to town to get the grant.

My biggest problem is child-headed households, once the parents have died, to try and get birth certificates is almost impossible. Just this week I had a case. A boy who is 17, and whose younger brothers are in the school, was desperate to get an ID for the mother so he could get a birth certificate and an ID. He was so desperate because he knew his mother was dying. Once the parents are dead it is so difficult.

This boy's story is so sad because it shows how these children are being treated and how people in government do not do their jobs properly. We had applied for an ID for the mother, but then he came to me on Monday to say she was so sick. He was so distraught. He said he had gone to the clinic to tell them she was so sick and they said 'Put her in a wheelbarrow and bring her here. The ambulance cannot come to you and it will only come late anyway'. He was so distraught, 'How can I put my mother in a wheelbarrow? She is so sick,' he told me. So I have an arrangement with the taxis here so they went to fetch the mother and took her to hospital. We heard she died on Wednesday.

Even that was not done properly. People here have no phones so the hospital phoned the police station and they should have gone to tell the children straight away. Instead they just told everyone around and the children heard it from people in the street. On Wednesday they came to me to ask if it was true. I had to find out from the hospital. I had to tell them.

The need is so great that I sometimes feel overwhelmed. As I fix one problem another comes up.

School fees

With school fees I just say, that is not my priority. I laugh when people say I cannot run my school without fees. I do. In 1998 we agreed that our school fees would be R20 a year per family but even that is too much for many families here.

We manage and we are a beautiful clean school with books and stationery. I have organised some donations but mostly it is because the parents care about the school and the community and if they have money they give and if not they come and clean and fix things and cover books and work in the garden and work in the feeding scheme. The community feels this school is theirs. Last year someone stole the gas that we used for making oats porridge in the morning and the community was so cross they told the police to search and find it. Now we have no more break-ins. The community would not tolerate it.

In January this year I asked through the children for people who were HIV positive to come forward and not be afraid and disclose and we would start a support group. So people came, sisters, aunts, mothers and some fathers too.

I wanted the children and the parents to know it was not a sin to have this disease and that we could talk about it.

Without this openness we could not really help the children because all the time we would not be wanting to admit that their mother was sick with HIV and AIDS but now we can just talk and help anyway.

Another reason why I knew I had to start with getting people to disclose status was that I could see that children were being hurt because parents were in denial. Children were being beaten and parents were angry and bitter and the children were suffering. So I spread the word – if you need someone to talk to, a shoulder to cry on, the school is the place. I told the clinic they could send people to the school.

Now we have a support group of parents and other community members running from the school. They are so open and so proud of the group they even boast about it!

Food gardens in school and community

I also knew that support was not enough. This is a very poor community. People have no jobs and when parents cannot make a little money from hawking or going out to the farms the children suffer from hunger.

Last year I started a food garden at school and this year we got families to start gardens too. I started with four families and we encouraged them saying it would be a competition for the best home garden – they all won a prize because they were so good.

This inspired their neighbours and now there are many gardens in the community. It is permaculture gardens and a local NGO helps from the school. Even small children come and ask for seedlings. Today I had two Foundation Phase children saying the ground is ready and can we have seedlings. Our place is so green now. There are many food gardens in the homes.

The food garden at school also feeds the children here at school. We have the government feeding scheme but it only gives bread and jam. I asked the Nutrition Project if they could give me the money that they spend on bread and let me use it as I know with that same money I could provide two good meals a day for children from the vegetable garden, but they refused. It makes me mad because they are saying that local people cut the bread and it benefits the community but the local people never get paid. We could run our own scheme here and use our vegetables.

Accessing grants

I have the help of a local church. They give me food parcels because some times I get a case at school where a family is just so desperate and then I can help with a

Case study 2: What schools can do

An interview with a principal

This project comes from my heart. For my children in my school. They have so much potential – they deserve this – it is nothing special, it is what they deserve.

Breaking the culture of silence

I was experiencing a problem in my community, at first people would not talk about HIV and AIDS. The clinic wasn't doing any HIV/AIDS education. It was a secret disease. I never knew anyone that was HIV positive. But children's parents were getting sick and I knew. It was such a threat that people kept quiet. I used to ask the children, why are your parents sick and they would say 'They are bewitched'.

Then all of a sudden last year people started to die - parents of children in the school. I knew it was AIDS. I could pick up the signs that they were dying of AIDS. It was so many that I had to do something. I discussed it with the teachers and they were also keen to do something even though there was also fear in the staff about this disease and what would happen when we talked about it.

So I started with programmes in the classroom. I got all these lovely materials but the teachers did not use them they did not do anything with them. By this time I was going into the community visiting children's homes and I realised how bad it was out there. I realised children were nursing sick parents, some as young as Foundation Phase! I could not stand and do nothing. It came from my heart. I knew that I had to find out first which children were affected by it and the way to do that was to get them to tell me.

So I decided to talk directly to the children myself. I made my assemblies dedicated to talking about AIDS. First I did education so they knew what it was and how it could be got and how not. I started to say it is not a disease to be ashamed of. Then after some time I started saying if you have someone who is sick at home I am there to help. I told the children 'if you have a problem I can ask people to come and help you'. At first no children came but slowly they started to ask for my help.

At first teachers were not interested but the assembly talks began to affect them too. Then two young teachers who took an interest were appointed here and they began to support what I do and now the others are beginning to follow, there is a little bit of competition now. The culture of the school is changing. I am always saying to teachers 'If you are going to teach well you need to know what is happening at home'.

Community and school together

I brought the parents in from the beginning. I knew it had to be a community response not one from the school only. The community had a problem that was affecting the school and children's learning so the community had to be involved in the solution!

- I like break time at school. I play at playtime, it is very nice.

On my side I can say school is a nice place where you can forget what is happening in your day. After school is when things start to get to be a problem. Then you have to think about food for younger ones but school gives a rest from problems.

School plays a very important role as I stay at home alone. At school I meet people who can advise me. If I did not have school I do not think I would be surviving. There is a guidance teacher who advises me and I tell her my problems and she listens to me.

The last two quotes show that, in spite of the problems, schools are a positive factor in these children's lives. They are a place where they can be children and get away from their responsibilities. They are a particularly important contact with the outside world for children whose world is restricted to their homes and their immediate community because of poverty.

The group discussed how *Soul Buddyz* could deal with some of the issues faced by children who were living alone without adults.

If they can show on Soul Buddyz the bad part of how the people are treating those of us who do not have parents then maybe people will be shy to treat us like this.

- Soul Buddyz must show different people. That there are people who are suffering and people who are ok. We want our story on Soul Buddyz.

- Yes. That will be right.

I think there must be a caretaker (child heading a household) on the TV programme that shows the problems we have.

The children in the group talked about the fact that mostly what they wanted from school was understanding. They wanted teachers and principals to find out about their home situations and to show understanding.

A good school will be where it is very nice and no one come and shouts at you and is cross to you. There will be people who will look after you and ask how you are doing. This will mean children will not leave school, like me. They (teachers) will come and find out about your life.

Teachers will understand your situation. It will be a very nice school because we will be taught by teachers who understand your situation. The one who can afford to pay will pay for you and no one will shout at you because you have no money. People in the school will understand each other.

The group agreed that principals were less understanding than the teachers.

- *The principals cannot understand, they are worse than teachers.*
- *They are not there most of the time. We are not talking with the principal, just with the teachers. The principal does not care.*
- *The principal, haai. He understands nothing, they cannot listen or even talk nicely they are worse than teachers.*

Most children did, however say there were individual teachers who were supportive.

- *Last year there was one mistress who understood about problems and if you could not pay fees or uniforms. There are few and very few, most are hard.*
- *I have never had a nice teacher.*

Mrs T is understanding us. Mrs T was good because she treated you equally. If you did not have money she took money from her pocket and gave for you. You could tell her problems and she did not tell others.

I was having a teacher like a mum to me – she did bring the food from home for me and she brought me clothes and sometime I would wash the car for her and she understood.

I was having a problem with the fees at school and that teacher understood me a lot and sometimes on a Friday I would wash his car for money so he understood my situation.

In spite of the negative experiences at school the group also agreed that school was a positive thing in their lives.

- *It is nice at school. I write.*
- *I like ball.*
- *I like to meet my friends at school. We talk and play games. I like playing at school.*

If the minister of education came here I would tell him to tell teachers I cannot afford to pay school fees and they must not ask me every day. They ask me every day. Every day they ask where are fees. I am sitting in class worrying about the younger ones coming home and I have no food for them and what will I feed them and they are asking me about fees.

The younger children talked about how they are teased by other children at school.

It happens most of the time that they tease you and say you don't have parents.

One girl who looked after two younger children described how the community also labelled children from child-headed households.

I understand when children do it (call children names) because they are young and don't know, but adults say these children are naughty because they don't have parents. That is hurting. They are saying they are bad without knowing them.

When asked who they could turn to when they needed support some of the children said they had no support at all.

There is no one at school who is nice. There is no support from a teacher. They all shout especially about the polish (polish for the desks at school). Even when they say bring extra books and I don't have – they shout and ask, 'So where are you going to write?'

- There is no one to talk to. No one cares about us. They just go and play and you are supposed to be OK.

- I am unhappy and there is no one to go to. Only granny. I trust only my granny - no one else. (Granny is blind and 80 years old).

Those feelings (sadness) are coming out and sometimes I feel that it is better to leave school as no one asks me what is wrong. No one cares. I sometimes feel that it is better to leave school so I can at least find some money to buy food for the other children.

Some of the things that make me want to leave school is my younger brothers are suffering and I feel like I need to do something and get a job. It is the suffering at home.

The last quote raises the issue of leaving school which. This was frequently mentioned by the older boys who were in school. There is strong pressure on them to find money for the family and this, coupled with the negative environment at school, is clearly a reason why many older boys drop out of school. Three of the boys in the Caretaker group have dropped out of school.

4. Case studies

Case study 1: Children from child-headed households speak about school

Ekupholeni Mental Health Centre works in Kattlehong outside Johannesburg. They offer a comprehensive community mental health service. Much of their work is based around supporting those infected and affected by HIV/AIDS. About six months ago they started a support group for teenage caregivers of younger children. The group is called the Caretakers. They range in age from 17 to 24. Most have sole care of at least two children who range in age from 6 to 18. One or two live with a grandmother or an ill parent.

Some of the members of the Caretaker group brought the children they care for to a meeting where we discussed the needs of children in their situation in relation to school.

One of the biggest problems for them was that they could not pay school fees.

Sometimes before I had a school uniform (the centre bought the group uniforms) they liked to tease me and say it is very cold and they said 'you don't have jersey' and I felt very bad when they say this.

- Teachers beat us when we don't have uniform. They beat us because we are supposed to have donation for cleaning materials and when you don't have, the teachers say you must bring.

- They force you and push you and say 'tell that person who looks after you to give money'. And they say 'how come you don't have. Tell that person to give you money'.

School fees is a big problem. If you try and explain that you do not have school fees they say 'Why are you here? Who sends you to school if they don't have fees'?

Last year she (referring to a younger child) did not go to school because there was no uniform and fees. Only this year could she go because Ekupholeni paid fees.

The issue of school fees needs to be seen in the context of the extreme poverty that the children live in. All of the families have no income at all. The children struggle for food every day. They live mostly off the kindness of neighbours. Worrying how to feed the younger children is a constant worry for the older ones. The older children talked about how this responsibility affects their schooling.

Lack of concentration in class when the mistress is teaching because you are worrying about what is happening at home. Don't concentrate and when there is a test or exam you don't do well because you are worrying about what is happening at home. Younger brother and sister are going to come home and then they will want food and where are you going to get food?

somebody and him to somebody, and then he can concentrate more on his schoolwork. (coloured area)

This is logical because schools are one place that children who are alone have access to adults who have some power. What is interesting is that the children in all groups see teachers as a potential source of help for children in need. This is probably because they are often the only adults they come into contact with.

Analysis

In spite of government projects to stop the practice it seems that schools still regularly harass children who cannot pay fees or for uniforms. It also appears that there is little open discussion of HIV/AIDS in schools. There is some learning taking place in Life Orientation lessons but this does not seem to affect children's attitudes and misconceptions still abound.

There is little emotional support for children when a teacher or parent dies. Memory rituals are an important part of helping children cope, yet these seem to be absent from school life. It seems to be only isolated teachers who are doing anything to help children cope with grief.

The fact that teachers are seen by children as an important source of support is backed up by the comments made in the case study where children say that even though schools are difficult places for them they are important because they are the only place they go to outside of home. Schools are institutions that most children, even the poorest children, have access to. It is logical, therefore, that they see schools as potential places of support.

Yet it is also clear that schools are not offering any kind of institutional response to the needs of vulnerable children. It seems that help comes only from individual teachers.

HIV positive until you test. Children should know that HIV is a normal disease and we all have to accept it. (township)

They also need to teach the children more about AIDS to know that you can't get AIDS if you kiss somebody or play with somebody. (coloured area)

Emotional support at school

In all but three of the schools children could identify one teacher that they were able to talk to about emotional issues and about problems at home. The main attribute that these teachers had was that they listened and did not tell others about their problems.

- *We would talk to Mr C.*
- *He teaches Life Orientation and Culture. Guidance counsellor.*
- *He took the grade 7's last month to Nkosi's Haven I think.*
- *Why do you think he'd be a good person?*
- *'Cos he's understanding.*
- *Because he helps people if they have got problems. You go and you speak to him and then he'll organise it and he'll talk to you about everything.*
- *I would speak to him if I had a problem because we know him, most of us know him, we have been speaking to him.*
- *He doesn't go and tell other people. He keeps it to himself but he just suggests things. He lays out the options and helps you think it through. He does not just tell you.*
- *He's also very kind and he's epileptic and he also used to work at a psychiatric clinic.*
- *He tells about his own sickness.*
- *He solves all the problems. (suburban)*

All groups agreed that children need someone at school to talk to.

- *If they can have someone to talk to, things will be better for them.*
- *They have to talk with themselves (each other) and come up with the solution.*
- *They need someone to encourage them to move on with life and stop thinking about their parents. (township)*

Helping children meet their practical needs

In the groups children talked about how teachers in particular could help children in difficult home circumstances. Their suggestions about what teachers could do were often wishful thinking.

In all the groups children are clearly aware of social services such as social grants but they see schools as a way to access these social services. They talk about going to a teacher and the teacher going to the social workers to get help.

He can go speak to the principal and tell the principal that he just stays with two sisters and he can call in the welfare. And they can give the two sisters to

- *They ask you to say how much do you earn? They look at how many children in a family. Average in the family.*
- *They investigate and they say okay. (suburban)*

In one school where there was a comprehensive programme to help vulnerable children, children were not expected to pay fees.

What happens with school fees? How do the principal and teacher handle this?

- The principal says she does not worry about this. She encourages them to learn even without paying.

What about uniform?

- I think the principal takes her children's small clothes and gives them to the children.

- The principal also buys them second hand uniforms that have got very little faults.

- She helps them because she cares for them

- During break she gives them two slices of buttered bread and jam and sometimes gives them eggs

- She takes them to the social worker. They take the children and give them everything that they want from the grant money. (township)

When children were asked to talk about what schools should be doing to help children all groups mentioned that schools should help with fees. Interestingly none mentioned that the fees exemption system should be implemented but rather talked about individual teachers helping the children with their fees and uniforms and also with food and soap. It seems that this is the norm. Children are not aware of any kind of institutional response from the school that seeks to meet their needs, apart from the one school mentioned above, and even then the children do not describe it as an institutional response but rather the result of a principal who cares. It seems that if children's needs are being met they are being met by individual teachers and principals who care rather than by any kind of institutional response.

Education about HIV/AIDS and preventing discrimination

In only one school (a township school with a comprehensive response to vulnerable children) did children mention that steps were taken to prevent discrimination against children affected by HIV/AIDS.

They could tell the teacher and the teacher reports to the principal and then the children (who did the teasing) are talked to and told to stop. The principal will then help the other children. (township)

In one suburban school children talked about education around HIV/AIDS and how they thought this had reduced stigma and discrimination. In other groups children mentioned the need for education.

I think all children need to be taught about HIV so that they can stop the negative attitude towards those children. I think no one knows that you are

by allowing children to participate in rituals such as funerals. This does not happen in every school.

Theme 4: How schools are meeting children's needs and what more would children like them to do

Fees and uniforms

It is clear that responses by schools to the needs of children vary from school to school. In this work the responses range from complete disinterest in the children's needs and a school that has a comprehensive programme that tries to meet a wide range of needs.

This is how children in some of the groups described what would happen if children did not have school fees in their school.

– Principal don't allow these children to come to school if they don't pay school fees. He says it is not his fault that their father died from HIV because he didn't send him to get the disease.

– Principal may also say don't bring them to school because no one can pay school fees for them.

– Teachers will encourage principal to send these children home because they don't pay school fees. (township)

- What happens to the children if they cannot afford to pay school fees?

- They beat them.

- They send them home.

- They tell them to go home to look for the school fees.

- They tell them to go home to look for the pens and books so that they can be right.

- They ask them to go home to look for their pencils.

What do they do if they don't pay school fees and don't wear uniform.

They send them home to get the uniform. (rural)

The principal will send letters to their mother every day to tell her that the school fees are not paid yet.

They can be suspended.

- They won't get their reports.

- They also won't get books or pencils to write with.

They are not allowed to write exams. (coloured area)

In one school it seems the fees exemption system as required by the Schools Act is operating and children are aware of it.

- Some people like can't pay, let's say for the school fees. The school gives it to them free, some people

- The school helps if people struggle financially.

had died, little would be done to help children cope with the loss. However, some children did say they would attend the teacher's funeral.

- *Yes. They ask children if they do not miss their teacher.*

Researcher: Does that happen here in your school? Has someone died here?

- *Yes, we talked about it. Mrs x died in a car accident and the other teacher went with us to her funeral and we all cried.*

- *We talk about her even now. (township)*

One child described how he remembered a teacher who had died.

By sitting on her desk and chair during break. (township)

Some schools are clearly not doing anything to help children cope with the loss of a teacher.

- *They feel sad.*

- *They think about her when they write.*

Do children talk about the teacher who died?

- *No.*

- *She is no longer alive.*

- *They say the teacher left them forever.*

- *They do think and miss her.*

- *They worry about her even if they don't talk.*

Do other teachers talk about her?

- *They don't talk about her.*

- *Children think about her when they see her writing on the chalkboard.*

Do other teachers talk about her to children?.

- *No.*

How do children remember her?

- *We miss her by repeating things that she liked to say or talk about.*

- *We remember her by seeing her writing on the chalkboard.*

Does the school do anything special to remember her?

- *No.*

Have you had a teacher who died at your school?

- *Yes. (rural)*

Analysis

It is clear that many children have experienced the emotional impact of illness and death in the family. They describe children's responses in detail. Perhaps most important in the context of *Soul Buddyz* is the way that children have experience of how emotional issues impact on schooling.

Children have experience of the death of teachers. It is also clear that the death of a teacher leaves children feeling very sad and anxious.

It seems that there is little formal response to help children cope with the death of a teacher. Responses include helping children cope by talking about their teacher and

- *They won't be able to concentrate on the job at hand in school. They'll be thinking about things back at home.*
- *They won't understand what is being taught.*
- *They'll think about the fact that their father has died and their mother is sick.*
- *Or think of leaving school so that he can take care of the mother.*
- *They'll think about being orphans after being left by their parents.*
- *They'll worry about finding their mother dead after school*
- *Maybe they're worried they've got Aids. (township)*

Only one child mentioned getting help from a counsellor.

- *They can get psychological help.*
Researcher: What is that?
- *When they see a counsellor and she helps them to talk and then feel better. (coloured area)*

Interestingly a few groups suggest that if their practical needs are met the children would not be as sad.

- *Sometimes they are sad*
- *If they are staying well, and they are happy, they do not think that much. They feel like their parents are there even if they are not there.*
- *It would be nice though if some children were not teasing them and they were eating nice food. They would feel happy. (township)*

How schools are coping with the death of teachers was also explored with children. Most often it seems that children are told about the death of a teacher in assembly or by their own teachers.

Principal is going to tell all children.

They were told at assembly about it.

Principal is the only one who can tell children about a died teacher.

Principal will go class to class telling all the teachers about the teacher who died. Then the teachers can tell children about her.

In all groups children agreed that losing a teacher would make children feel very sad.

- *They don't feel good.*
- *They cry when principal tell them about the bad news.*
- *They give up when principal tell them about the sad news.*
- *They start to cry when they hear the sad news.*
- *They became angry to hear the news. (rural)*

The response of schools to the death of a teacher varied. In most schools it appears that apart from teachers talking informally with the children about the teacher who

- *They don't have pencil*
- *They don't have school fees*
- Researcher: What do others think?*
- They don't have food that they can eat at school*

Analysis

The discussion shows that children have detailed information about the practical needs of those children who have been orphaned or who have ill parents. These needs relate to school fees and clothes and food. The degree to which children experience poverty was related to the area in which they live. Children in the rural groups were obviously the worst affected by poverty.

Theme 3: What psychosocial problems are facing children affected by HIV/AIDS?

Children described a number of psychosocial needs experienced by children affected by HIV/AIDS. These included the fact that the children would be sad because a parent had died, they would worry about their mother at home. Children said they may have to look after someone who is ill. They also said they would worry about their own future should their mother die.

The interesting point is that all groups said this would affect children's performance at school.

- *They could be sad*
- *Emotionally destroyed*
- *Yes*
- *Very terrible (suburban)*

- *They feel sad.*
- *They always think about their parents – that makes them feel sad.*
- *They always cry.*
- *They are always sad. (rural)*

- *They can't concentrate on their work because their mother is sick.*
- *They don't listen when the teachers speak.*
- *Basically they fail. When the teacher gives them work they cannot do it.*
- *They have schoolwork problems. They cannot concentrate on their schoolwork. Because they think about their mother.*
- *Because they think about their mother at home who is sick. (coloured area)*

- *They think that they will struggle if their mother also leaves them.*
- *It is difficult for them at home because their mother can't stand up. She is sick. She is not even able to cook for them.*
- *They won't always be at school because they'll have to take care of their mother.*
- *They will worry and think that other children will tease them at school.*

- *He will never have money because he is not working.*
- *He will never be able to feed his younger siblings because there is no food.*
- *He is thinking what will the children eat back at home.*
- *He is wondering who is taking care of the children.*
- *He is thinking what he will eat when he comes back.*
- *He is wondering where he will get school fees money when he needs it.*
(rural)

- *Other children will be having Christmas clothes and they wont have.*
- *They don't have clothes, shoes, even soap to wash themselves and clothes.*
- *They don't have paraffin. (township)*

Another practical problem mentioned by many groups in relation to children heading households was that the younger children were a worry to school going children.

It will look like these children are dependent on him. He can't play. If he goes to play, the children starve. It is as if they are expecting him to go and ask for food, such that people in the neighbourhood, they are tired of him. They know that if they see him, he is going to ask for food. (township)

The suburban groups did not talk about the children's practical problems apart from struggling with school fees. This suggests that there is less experience of real poverty related to HIV/AIDS in these areas.

The most striking transcript related to practical problems came from the Limpopo rural group. According to this group the problem of hunger would be overwhelmingly the biggest problem they faced. The discussion kept going back to food and hunger no matter where the researcher took it.

Researcher: What problems do they have?

- *The problems that they face - they suffer from hunger.*

Researcher: Okay. What do others think?

- *They do not have food.*

Researcher: Besides food what else can be a problem in their life?

- *They don't have water to drink because they don't pay services because there is no money.*

Researcher: What do others think?

- *They don't have money to buy food.*
- *They don't have clothes to wear*
- *They don't have shoes*
- *They don't have jersey to wear when is cold.*
- *They don't have school uniform*
- *They don't have money to buy books*
- *No one pay school fees for them.*
- *They don't have food to eat and they became thin because of hunger.*

Researcher: We want to know what problems do they have at school?

- *They don't have pens so that they can write*
- *They don't have books*

- The parents will stop their children from playing with those who have a sick mother.*
- Their friends will also tell other children in the community and all children will isolate them.*
- As soon as children start to tell the teacher, is the time where other children start to isolate them.*
- The relatives also isolate them because they won't let their children play with those two children. (township)*

Analysis

It is clear that wrong information about transmission is still common. This leads to discrimination. In the above quotes the children link discrimination to the threat of transmission. One group of children even made the link between their knowledge and their choice not to discriminate against affected or infected children.

It is clear that children have experienced and seen discrimination from other children, teachers and management at school. They also talk authoritatively about why it would not be a good idea to disclose the fact that someone in the family had HIV/AIDS.

This suggests that there is still a need to keep repeating basic information about transmission of HIV/AIDS in order to break down discrimination. It is also clear that according to children the climate for disclosure does not exist in most communities.

Theme 2: What practical problems are facing children affected by HIV/AIDS?

All groups mentioned that the children would have practical problems. The most frequently mentioned problems were related to school needs. Children affected by HIV/AIDS battle to get uniforms, school fees and stationery.

- They don't have uniform, stationery. No one provides them.*
- No one wants to borrow them the stationery because other children are scared of being HIV positive. (township)*

*They struggle with school funds because their mother is sick now.
The principal will send letters to their mother every day to tell her that the school fees are not paid yet. (coloured area)*

In addition some groups also mentioned that the children would struggle for food at home.

- They don't have clothes.*
- They do not have food to eat because their mother is not working*
- They need paraffin and tea bags. (township)*

This is how children discussed the worries of children who are heads of households.

– The SGB (School Governing Body) will send these children home because they're scared that these two children will spread this disease to their children. (township)

One group of children discussed the fact that children in the school who had some knowledge would probably not discriminate against them but others who did not know the facts, would.

– Probably about 60% of our school would be all nice, especially nice to them and 40% would be good and 60 or 70% would be nasty.

– And say "Huh, you got Aids"

– The grade 6's and 7's, I don't think would do it because they have been studying about it.

– And maybe some of the grade 5's but not the rest of the school – they would not like them.

Researcher: What do you know about it that would help you to understand them?

– Studying it, helps you know more.

– Like you know that you cant get AIDS by touching or playing with the children, only if

Researcher: You have sex?

– Yes, Unprotected.

– We've studied that in Life Orientation. (suburban)

There was one group that did not talk at all about discrimination. This was the rural Limpopo group where the discussion was dominated by the affected children's need for food.

Linked to the idea of discrimination is disclosure. In most groups children said that the affected children would not disclose their parents' status easily because of the threat of discrimination at school. Linked to this discussion was the idea that you could not trust people at school to keep it a secret.

- Probably everyone will know what happened to them, because normally friends will eventually tell someone and they will tell someone and they will tell someone.

– And then at the end.

– Next day everyone knows. (suburban)

- The children around the school will know.

- But the principal does not know because they are scared to say the wrong thing and he will expel them. They will have to tell someone they trust. If the principal finds out he will tell them that they must not come back to the school because you have AIDS. (coloured area)

– You find that friends tell their parents about what is happening in the life of those children and parents will keep spreading the news to the next door neighbour.

- *Maybe if they sleep with a boy who is HIV positive.*
- *Maybe they have touched the blood of someone who has AIDS.*
- *When you have an open sore and touch his blood. (rural school)*

In all groups children described discrimination.

Researcher: If people think you have it how will they treat you?

- *Other children might hurt them*

Researcher: Oh, like physically bully them?

- *Yes or throw things at them*
- *They will get embarrassed. (coloured area)*

They treat them bad, because they think they also have HIV.

The children make fun of them and call them names.

The other children do not play with them, because they think if they touch them they will also get HIV. (coloured area)

Researcher: How do people treat them in the class?

- *Badly. They laugh.*
- *Some throw papers at them.*
- *Some gossip about them.*
- *Some tell them that their mother has got AIDS.*
- *Others do not give them lunch.*
- *Some do not want to come near them.*
- *Some do not want to play with them.*
- *Some laugh at them because of torn clothes.*
- *Some laugh because they are not eating.*
- *Some say they are thin. (township)*

In this quote the discrimination is related to poverty as well as to HIV/AIDS (see below). Children also described teasing related to orphanhood.

Researcher: What do they say when they tease them?

- *Hey you without the parents, you are so silly. (township)*

Researcher: Does that happen here in your school?

- *Yes, they shout at the children with no parents. They laugh at them. (township)*

The discrimination that the children describe is mostly discrimination from other children. They do, however, also describe children experiencing HIV/AIDS-related discrimination from teachers and principals.

- *Principal may send them home because he is scared that other children may get their disease from these children*
- *They won't call them 'children', they will call them 'these things' as if they are not human beings*
- *Teachers will always talk about them instead of teaching in the classroom*

– *Some children, they're scared to play with them because if one of the children can bleed, they might be HIV positive.*

Researcher: Do you think these children are HIV positive? We said their father died from HIV/AIDS and that their mother is sick.

– *Yes that's true, but children think that there's a possibility of them being HIV positive because of their mother. Other children will see them as HIV positive.*

– *Some children try to make friends with these children who are HIV positive but people will think they're also HIV positive when they make friends with them.*

Researcher: What happens when they go to the toilets?

– *No one will agree to use the same seat of toilet that they're using.*

– *When they get inside the toilet, other children are going to leave the toilet.*

Girls won't allow them to use the toilets because they don't want to be affected by this disease

– *Children don't want to touch their stuff.*

- *Teachers will be scared to mark their books.*

– *They won't be allowed to touch the tap that our children use.*

Researcher: Even when they need to drink water, they're still not allowed to touch the tap?

- *They will be encouraged to bring their own things to use at school.
(township)*

According to these children there are still people who believe HIV can be transmitted through touch, and discrimination is the result of this misconception.

In one group children said that the principal would be the one who had the incorrect information.

- *He would probably expel them from the school because he does not understand about HIV.*

- *He will think that you can get HIV if you only stand by someone or kiss them.*

- *HIV can only be gotten through sex activity or blood. But the principal would not know this so he will expel the child, because he will think the child will infect the other children in the school. (coloured area)*

This quote shows that the children themselves have an accurate knowledge of transmission but that they are aware that many people do not have the same knowledge and what the consequences are for children when people do not have correct knowledge.

In four groups children mentioned transmission through blood. This was one way they thought the children may have become infected.

- *They have AIDS as well.*

- *Why?*

- *They might have it too and not go to school.*

Researcher: How will they have AIDS?

- *If they get it from their father.*

The next discussion is from the same group. Here they seem to believe that the virus could be transmitted through touch.

- They (other children) might really not want to touch the ball because when they touch the ball, they going to get HIV positive.*
- Because children don't want to play with them and touch them, they think they going to get the virus.*
- They don't want them to be there.*
- They don't have any friends, they just have to sit alone.*
- They don't let them play on the jungle gym and they say don't touch it because we going to play and you will give us the virus.*

No one in this group countered this idea. In another group some children seemed to have correct information but others were unsure.

- You could transmit it from your mom or dad.*
 - They might also get it.*
 - They will have it and their children may get it too.*
- Researcher: Do you think they've got AIDS because their father died of AIDS and their mom is sick with it?*
- Yes.*
 - No.*
 - Maybe – If their mother has it.*
 - There's a chance.*
 - Only if they were born with it or unless they touched blood or other blood.*
 - And they had a cut.*
 - 50 % chance.*
- Researcher: Why do you think they've got a 50 percent chance?*
- Because if your mom and dad both have AIDS, then you've got a 50% chance probably because...*
 - No about 75%.*
- Researcher: What do you others think?*
- If their mother had AIDS, then they will have AIDS.*
 - Yah they will have it.*
 - No, only if their mother had the virus when they were still in her tummy, the baby would have probably been infected. (suburban)*

In other group discussions children described how the two affected children would be discriminated against because people would make the assumption that the children were themselves HIV positive.

- They don't play. No one wants to play with them because they're scared to be HIV positive.*
- No one wants to play. Everybody will chase them away because they say they can't play properly. You find that they can play but people make an excuse by saying they can't play.*

3. Findings from participatory groups

In these groups the discussion was initiated by a scenario that involved hypothetical children. This was done so that children would feel able to talk freely as they were not talking about themselves. Another reason was that this approach created emotional distance from difficult situations. This emotional distance is particularly important when running short focus group discussions. In longer workshops it is easier to talk about emotionally loaded issues as one is able to deal with and contain the emotions that such a topic raises.

Children were talking about hypothetical children but in the context of their own school. A map was drawn at the beginning of the discussion to root the work directly in their own reality. In many cases children moved from discussing the hypothetical children to their own situation. In addition there is strong internal consistency in what the children said (i.e. within the group and across groups and in the case study). There is also external consistency with other research. We can accept, therefore, that what children are saying is a valid description of their situation.

Theme 1: Misconceptions, discrimination and disclosure

One striking theme that emerges from the transcripts is related to stigma and discrimination caused by misconceptions. In the participatory discussion groups children were asked to say what problems children affected by HIV/AIDS would have in their school. They were given a scenario to discuss. In this scenario two children of their age had lost their father to AIDS in the last year and their mother was also ill. They were then asked to say what problems these children might have at their school.

The responses varied across the different groups. In one of the groups it appeared that the participants held the idea that because the two children in the scenario have or had parents with HIV/AIDS they are also therefore infected.

- *They might be teased at school.*
- *The other children would get frightened. They won't get near them.*
- *Because they have it (HIV/AIDS) too.*
- *I was going to say the same thing.*
- *They must be feeling bad, because they might be banned from school.*

Researcher: Why?

- *They may have it too.*
- *They could even separate the class then say you are HIV, you are going into another class. You must not be in same class as others.*
- *Most of the other parents would get angry that those children might be HIV and they must not play with their children.*
- *They might look thin.*
- *They might act funny.*
- *They get skin rashes.*
- *They become weak.*
- *They like to go the toilets every time. (Indian area)*

		under apartheid	
Limpopo	11-14	Ga-Maja, traditional rural village 60 km from Polokwane	Sepedi
KwaZulu-Natal	11-14	Chatsworth, Durban, Indian area	English/Zulu
KwaZulu-Natal	8-10	Clermont, township area, Pinetown	Zulu
Northern Cape	11-14	Barkley West, small rural town	Afrikaans
Eastern Cape	11-14	Nompompolelo, shack area outside East London	Xhosa
Eastern Cape	8-10	Traditional rural area	Xhosa

Data analysis

Group discussion took place in the children's home language. All the discussion during the participatory workshops was taped, translated and transcribed. These transcripts formed the data that were then analysed. The transcripts were analysed using a standard qualitative data analysis tool, thematic analysis.



Research aims

The audience research on HIV/ AIDS and school aimed to understand:

- What children felt schools were doing to assist children affected by HIV/AIDS with their practical needs
- What children felt schools were doing to assist children affected by HIV/AIDS with their psycho-social needs
- How schools were helping children cope with bereavement at home and at school

It is important to note that throughout we looked at these issues from the point of view of children.

Research groups and activities

The research consisted of a series of participatory discussion groups held with randomly selected children aged between 8 and 12 from a diverse range of environments in 6 provinces around South Africa.

The following table outlines the range of groups who participated in the research around HIV/AIDS.

Province	Age group	Area	Language
Gauteng	8-10	Sebokeng, township outside Vereeniging	Sesotho/Setswana
Gauteng	11-14	Blairgowrie, suburban area in Johannesburg	English
W Cape	8-10	Factreton, Cape Town, an area classified 'coloured'	Afrikaans

which children could tell just as much of their story as they felt safe to tell. They did not probe about the details of a painful event, nor ask about a child's feelings. What the child offered was accepted, even if not all the details were present. Note that this applies only to information that was potentially painful. In other situations the researchers used secondary questions to probe for details.

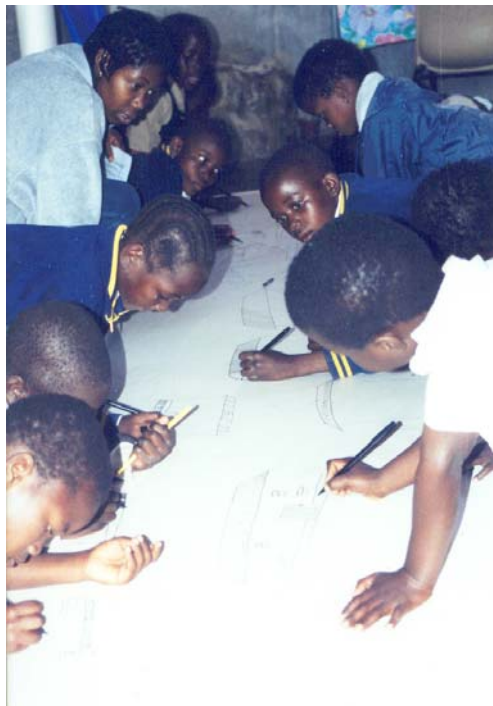
In addition, ensuring complete confidentiality of data was another way in which we sought to minimise harm. Particular schools are not named in the research report and descriptors are used to identify quotes.

Appropriate activities

To make sure the research was truly participatory group activities were devised in such a way that

...children's ideas and perceptions could be expressed in their own terms without being blocked or misrepresented by the ways adults think and talk.
(Boyden and Ennew, 1997, p45).

This meant that we used techniques that were less dependant on words, for example mapping and drawing.



We also attempted to reduce the power relationships between children and adults in the research process by playing games with children before we began the work and by working in a space where children felt comfortable.

This last argument is perhaps the most important in the context of the creation of *Soul Buddyz*. If we want a media vehicle that educates while it entertains, it must take into account the real problems and issues that concern young people. We can only do this if we allow them to participate in the making of the media at an early stage in the process.

Boyden and Ennew (1997) point out that if children's participation is to be more than token it needs to be devised in such a way as to take particular ethical issues into account and to make sure the activities are suited to the ages and stages of development of the children and youth. Both these issues were taken into account in this work.

Ethics

An adapted form of the ethical guideline for research work with children reproduced in Boyden and Ennew's (1997) publication on research with children (see Appendix 1) was applied in this work.

In addition another key ethical principle was applied in this research.

It is not ethical to expose a child already vulnerable to any additional risk through an investigation that carries no benefit for the child. Interviews about painful subjects should be performed with the principle of 'least harm' (Boyden and Ennew, 1997, p43).



Researchers who ran the focus group discussions were aware that some of the topics we were exploring could touch on sensitive and difficult issues for many children. The principle of 'minimising harm' was applied throughout.

Practically this meant that researchers made it possible for children to withdraw at any stage, were sensitive about issues which might have caused shame or embarrassment, did not challenge the child about answers given, and did not ask questions which could have been upsetting. They also created an environment in

Clearly, within the context of the CRC children have a right to participate in the creation of media such as *Soul Buddyz*. It is not enough, however, to say that children have a right to participate. It is also important to understand why they should participate.

Children's participatory rights are legitimated in a number of different ways. The most common arguments are summed up in the following three points (adapted from Kj rholt and Qvortrup, 2000).

1) The first argument for children's participation suggests that participation is in the best interests of children. It contributes to a positive development of individual identity, competence and a sense of responsibility.



2) The second argument for children's participation emphasises the way in which children's social participation constitutes an important area for social democratisation insofar as it represents the extension of some democratic rights to a disenfranchised group.

3) The third argument is that children's participation in social processes gives us access to essential information that we could get from no other source, thereby making society a better place for all of us. The following quote sums up this argument:

Developing better methods of working with children and enabling their participation is beneficial not only to children. By including some previously invisible groups we are making our research, our programmes and our communities [and our media] more inclusive, more functional and effective. Omitting a large sector of society means that everyone loses and fails to see the bigger picture. If we are unaware of the problems and issues that concern children and young people we cannot hope to devise strategies or solutions [or media] that will address their concerns, and will constantly be struggling to make sense of the world without some of the vital information we need. (Ivan-Smith and Johnson, 1998, p299)

1. Introduction

Introduction to *Soul Buddyz*

Soul Buddyz is a multi media edutainment vehicle created for 8 to 12 year olds. It consists of a television drama, radio drama and a book for use in the Grade 7 Lifeskills classroom. The first television drama series was aired on SABC 1 and the book was distributed around South Africa during 2001. The second series was aired on television in 2002 and the book distributed in 2003.

Based on the success of *Soul Buddyz* and *Soul Buddyz 2* Soul City is presently developing *Soul Buddyz 3*. *Soul Buddyz 3* will deal with the following issues:

- Financial management
- Gender and masculinity
- How schools are dealing with children affected by HIV/AIDS
- Nutrition

This report covers the HIV/AIDS and schools theme.

The Soul City research and development process

Over the years Soul City has developed a particular approach to the creation of a mass media vehicle such as *Soul Buddyz*. This includes an extensive consultation and research process that ensures that all stakeholders and target groups have input into the materials. The research reported on here is part of the target audience research for *Soul Buddyz 3*.

This research, along with a literature review and input from stakeholders, will be discussed at a message design workshop. The messages will inform the script writing process. Once the scripts have been written they will be tested with the target audience and only then finalised.

2. Research approach

Child participation

Children participate throughout the creation of the *Soul Buddyz* series. This strong commitment to child participation is motivated by a number of factors.

Firstly, the right of children to participate in issues that will affect them is enshrined in the Convention on the Rights of the Child (CRC), to which South Africa is a signatory.

States parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child... (Article 12 of the Convention on the Rights of the Child)

- A story that presents the situation of child-headed households and their problems in relation to school needs to be presented.
- It would be important to emphasise that schools are an important source of potential support for children who are heading households.
- The important role that caring teachers are presently playing needs to be emphasised in the series.
- The series should show an integrated response from the various sectors of government where different departments work together with the teachers and principal at a school.

Recommendations for *Soul Buddyz 3*

- There is still a need for education about how HIV/AIDS is or is not transmitted. *Soul Buddyz 3* should include this kind of information especially in relation to children whose parents are infected.
- Stigma and discrimination continue. *Soul Buddyz 3* should emphasise that everyone has the right to be treated with dignity and discrimination in any form, by adults or children, against children affected by HIV/AIDS is unacceptable.
- *Soul Buddyz 3* should role-model children showing empathy towards children who are orphaned. It should also give some idea of how children in this situation can be supported by their peers.
- The fact that being an orphan carries stigma and the effect of teasing on children who are orphaned needs to be opened up for debate in the series. Showing children talking about being an orphan and the discrimination they experience because of it may reduce the stigma attached to it.
- Children need to be encouraged to seek out and create peer support networks. In addition some practical strategies for making peer networks a reality need to be modelled in the *Soul Buddyz* series. The fact that the *Soul Buddyz* are already a support group makes this a particularly pertinent message.
- It is clear that HIV/AIDS is not talked about in most schools. *Soul Buddyz 3* should role model openness and discussion in schools. The school presented in Case Study 2 provides a model for this.
- *Soul Buddyz 3* should emphasise the importance of emotional support for children who have lost one or both parents. A school-based response to this should be presented. It needs to be a simple practical response that is attainable by most schools.
- *Soul Buddyz 3* should contain information on children's rights in relation to schooling. It should be made clear that corporal punishment and harassment relating to school fees and uniform are illegal. Children and parents need to be made aware of the exemption policy.
- Schools need role models and strategies for helping children cope with the death of a teacher.
- *Soul Buddyz 3* should present a school that finds out about children's home situations and is understanding about it.

Contents

	Page
<u>1. Introduction</u>	1
Introduction to Soul Buddyz	1
The Soul City research and development process	1
<u>2. Research approach</u>	1
Child participation	1
<i>Ethics</i>	3
<i>Appropriate activities</i>	4
Research aims	5
Research groups and activities	5
Data analysis	6
<u>3. Findings from participatory groups</u>	7
<i>Theme 1: Misconceptions, discrimination and disclosure</i>	7
<i>Theme 2: What practical problems are facing children affected by HIV/AIDS?</i>	12
<i>Theme 3: How schools are meeting children's psychosocial needs.</i>	14
<i>Theme 4: How schools are meeting children's needs and what more would children like them to do</i>	17
<u>4. Case studies</u>	21
Children from child-headed households speak about school	21
An interview with a principal	25
<u>5. References</u>	30
<u>6. Appendix 1: Statement of Ethics</u>	31

Research conducted for Soul Buddyz by



Clacherty & Associates
Education and Social Development (Pty) Ltd
Address: PO Box 613,
Auckland Park,
2006, South Africa
Telephone: (+27) 011-482-4083
Fax: (+27) 011-726-3633
E-mail: glynis@clacherty.co.za

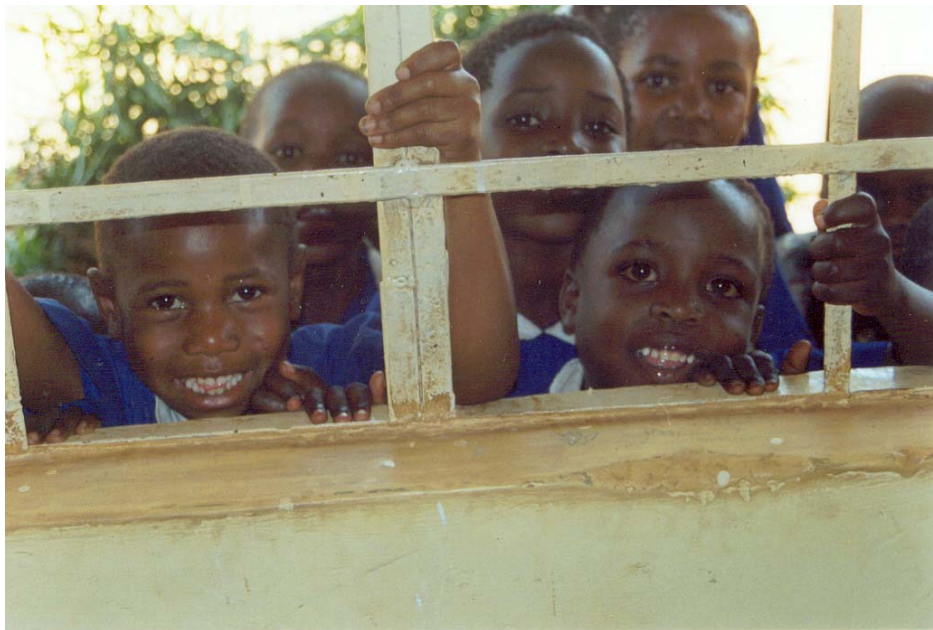
Soul Buddyz 3

Audience Research

Children's perceptions of how schools are providing support for children affected by HIV/AIDS and what they think they should be doing

A good school will be where no one will come and shout at you and be cross with you. There will be people who will look after you and ask how you are doing. Teachers will come and find out about your life.

This will mean children will not leave school, like me.



**Soul
Buddyz**
tomorrow is ours