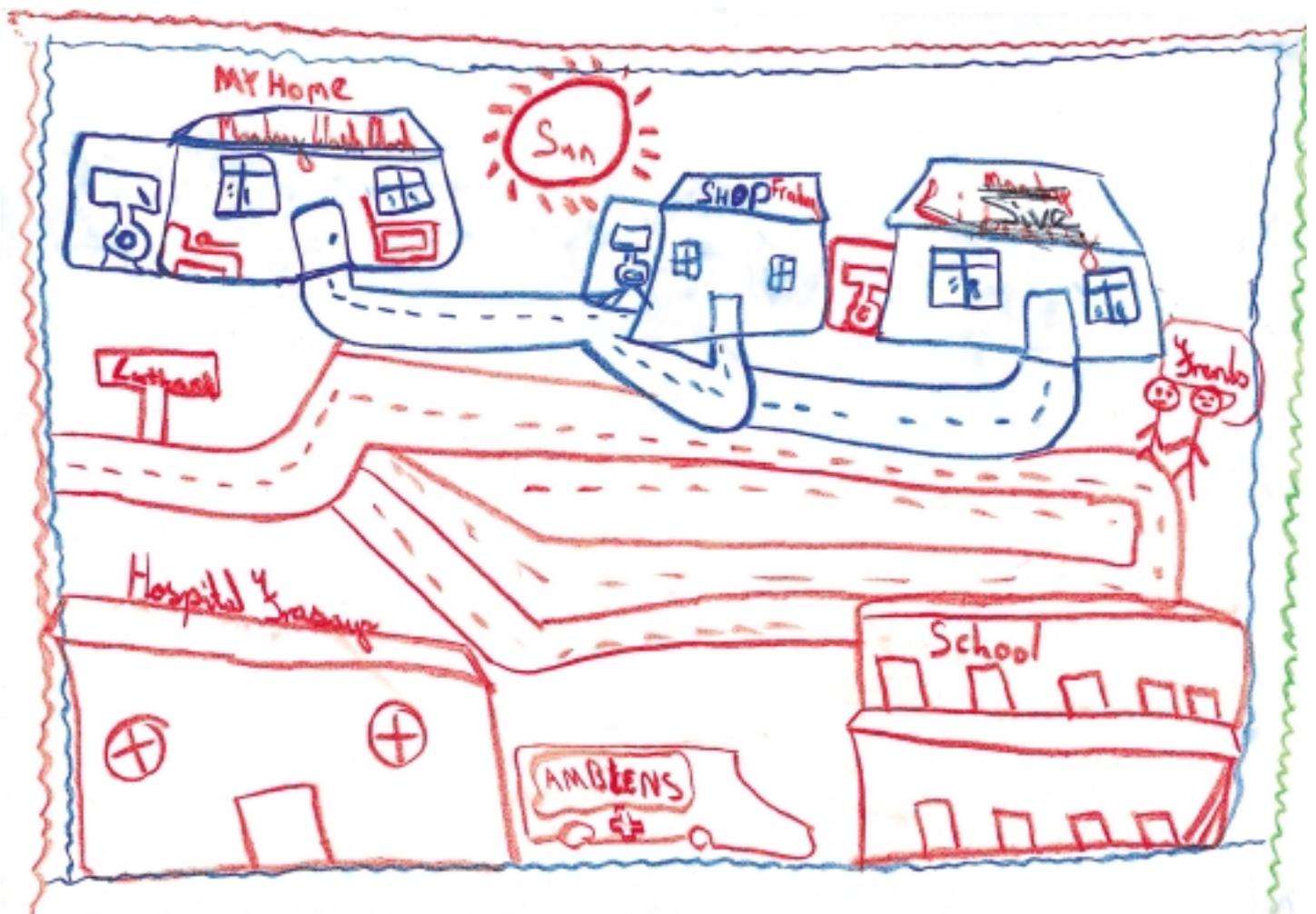


# STIGMA and Discrimination

4



## 4.1 The right to be protected from unfair discrimination

### The Constitution says:

- Everyone is equal and has the right to equal protection.<sup>23</sup>
- Equality includes the full and equal enjoyment of all rights and freedoms.<sup>24</sup>
- The government may not unfairly discriminate directly or indirectly against anyone on one or more grounds, including race, gender, sex, pregnancy, marital status, ethnic or social origin, colour, sexual orientation, age, disability, religion, conscience, belief, culture, language and birth.<sup>25</sup>
- Everyone has inherent dignity and the right to have their dignity respected and protected.<sup>26</sup>

### What do these rights mean for children?

- The government has a duty to promote and achieve equality and all persons have a duty to promote equality.<sup>27</sup>
- Government, with the assistance of the Human Rights Commission and other constitutional bodies has a clear duty to develop an awareness of the rights of people affected by HIV in order to promote a climate of understanding, mutual respect and dignity.<sup>28</sup>
- If unfair discrimination is occurring on a large scale, against a group of people, such as people with HIV, government has a duty to develop an action plan to address the unfair discrimination.<sup>29</sup>

## 4.2 Children's experiences

Every one of the 9 groups of children raised the issues of discrimination and stigma as key problems faced by HIV-affected children. They described experiences of discrimination against children who are HIV+, against children living in households where someone is HIV+ and against children who have been orphaned as a result of AIDS.

“ They call you a ghost while you're still alive. ”

### 4.2.1 “Your mother brought you into this world but she doesn't give you support”

Discrimination against HIV-positive children happens within these children's homes. Children who are HIV+ spoke about their families' reactions to their disclosure. Other children had friends or siblings who were infected and related their experiences.

“ Even though people know about AIDS, the challenge is that they don't accept you. People encourage disclosure but their actions are negative towards us. Actions speak louder than words. ”

**Ncobile, 16 years old:** “Sometimes you are accepted by others at home when you tell them. But others pretend to accept you, like in my case. After some time, say a week, you realize something is happening. You'll realize that there is that spoon, that plate, that cup that is used by you only. Maybe you are used to washing your sister's baby, like me. My sister's child liked it when I washed her. She would ask me and I would. All of a sudden when she asked me to wash her, her mother said that I should leave her, she'll wash her on her own. Then her mother will take her from me if I am carrying her. She would do funny things. I was not chased away from home but my sister cannot eat what I have cooked, my relatives cannot eat what I have eaten, she cannot allow me to wash her child because she feels that I will infect her child. So I felt like not staying with them - because they are criticizing me.”

**Nthabiseng, 16 years old:** “My brother didn't listen to my mother before he got HIV. Now my mother knows that he is HIV positive. She will keep on shouting and calling him names that are not nice, like 'Setopo' [corpse]. You are the 'setopo sa donkie' [donkey carcass]. It is very hard for my brother because he doesn't get support from his mother. If as a mother you don't love your child, no one will love him. The child feels bad. They call you a ghost while you're still alive. The change in their faces when they see you is like they see rotten meat or something. Your mother brought you into this world but she doesn't give you support so that you can die

peacefully. No one is allowed to visit you in your room. It is hot, your room is dirty, you are smelling bad, no one wants to help to bath you. It is not nice at all."

**Tsakane, 18 years old:** "When you are HIV+, they force you to get an insurance policy even if you don't want to because they know that very soon you're going to die and they are going to make money through you. They do it as if they love you and they support you, but they are happy that they are going to be rich when you die."

**Douglas, 17 years old:** "People change. Treat you as if you don't belong to them. You find that they used to buy you something every month. When they know that you have HIV they stop doing things for you. They punish you for something you don't understand. It is difficult for outside people to love you while your own family doesn't care about you."

**Smangele, 17 years old:** "We face many problems at our homes, because some of our parents do not listen to us. We do not feel free around them because some of them are abusive. They do not even give us a chance to explain what happened to us. Sometimes when they find out that you're HIV positive they do not allow you to go out. It feels like you are cut off from the world."

**“ It is difficult for outside people to love you while your own family doesn't care about you. ”**

#### 4.2.2 "If somebody [in the household] is HIV+, children live with trauma"

The children spoke about the social ramifications of living in a household where someone is HIV+. When one member of a family is thought to be dying of AIDS, the children in that household are often labelled as being HIV+ and sometimes the household is said to be bewitched. The children's experiences in schools, taxis, shops and other community settings highlight the extent to which HIV-affected children are discriminated against and victimised.

**Lindiwe, 15 years old:** "Not that I have HIV, but they call me HIV positive because I am staying with my brother and he is HIV positive. This happens in school. Other children might even think that I will infect them."

**“ When your family member passes away, they say that you are also dead or that you'll also die. ”**

**Tsakane, 10 years old:** "If one person in the family has AIDS, people will say that the child is also sick, even if she is not."

**Joseph, 9 years old:** "If one person has AIDS, people will think that the child is going to infect them."

**Thandi, 15 years old:** "Children encounter a lot of problems in the communities. When your family member passes away, they say that you are also dead or that you'll also die. If there is one person in your family, whether it's a man or a woman, who has died of AIDS, the community says that you too have got AIDS."

**Itumeleng, 7 years old:** "Relatives say that someone has been bewitched when they are sick. Children get sick and no one takes them to hospital."

**Douglas, 17 years old:** "If somebody is HIV+, children live with trauma. Everybody talks about their parents. It is not nice because these children still love their parents even if they are HIV positive, it does not mean that people should discuss their illness. How they get it is not important because it won't make them HIV negative. People don't want to accept and respect people with HIV/AIDS."

#### 4.2.3 "If you are HIV+, some taxis don't allow you in"

The children also spoke about what it was like to be HIV+ and about how HIV+ children are treated in public settings.

**Ncediswa, 14 years old:** "One of the students was laughing at the other one saying, look the hair is being removed and she is getting thinner, really they are about to take him - and the child cried."

**Lefa, 10 years old:** "People do not want to see her, they don't want to touch her. They swear at her. They gossip about her and they tell others that she is living with HIV"

**Mzingisi, 16 years old:** "If you are HIV+, some taxi's don't allow you in. You get embarrassed because everyone is watching."





The children spoke about the discrimination that they face in various settings, including at home, at the spaza, at church, at health facilities and at school.

**Vincent, 13 years old:** "People talk a lot about people who have HIV. They say you don't have a future. They think being HIV+ is the end of the world, and what I believe is that even when you are HIV+ you still have that dream that you work hard for."

#### 4.2.4 "You get what you deserve"

HIV/AIDS is seen by many as a punishment for bad behaviour and some children are left feeling that they brought this upon themselves.

A conversation between a group of children (aged 7 to 11 years), captured on tape and transcribed, shows the level of discrimination and victimisation facing HIV+ children.

**Tshepiso:** People pretend to love the child. They go and buy her sweets and later take her to a place where they are going to kill the child.

**Itumeleng:** They treat him badly.

**Lefa 1:** They do not give him food.

**Tshepiso:** They poison the person.

**Tsakane:** Because they do not like the person.

**Sefale:** They hate the child.

**Itumeleng:** People say the parent has been bewitched.

**Lefa 2:** They do not respect you.

**Boitumelo:** People are supposed to help you.

**Wilma, 12 years old:** "People think it is a punishment for being naughty. They say you get what you deserve".

**Morene, 14 years old:** "The people's actions are different to their words – they need to be informed about HIV/AIDS. The media tries but people need to understand that HIV/AIDS is not a punishment".

**Delani, 16 years old:** "People want to know how you got it. This will determine their attitude towards you. If you've got it from a boyfriend, they will have a negative attitude towards you because they said you've got what you wanted".

**Nthabiseng, 16 years old:** "They should learn how to treat a person with HIV/AIDS. People must stop criticizing them because that makes them feel bad about themselves. Most people they are dying because of blaming

themselves. They don't die because of HIV/AIDS. People who have HIV/AIDS they need support and love because talking about how they got it is not important because that won't make any difference".

#### 4.2.5 "People run away from you"

Much of the discrimination associated with HIV is related to ignorance and in part to the belief that touching a person with HIV, or touching something that that person has touched, will give you AIDS.

**Sizwe, 11 years old:** "People want to chase you because they think the HIV will spread. They think that by touching us they will get HIV. If the shopkeeper knows too, he'll say what you want is not there even if you are looking at it. He'll say so because he is afraid to touch your money."

**Delani, 16 years old:** "In the shops people do not want to touch the goods you have touched, they stand in another queue. People run away from you. You become isolated from the community and refused to be served at the supermarket"

**Thabang, 13 years old:** "People move away from you in a taxi and they wipe the seat."

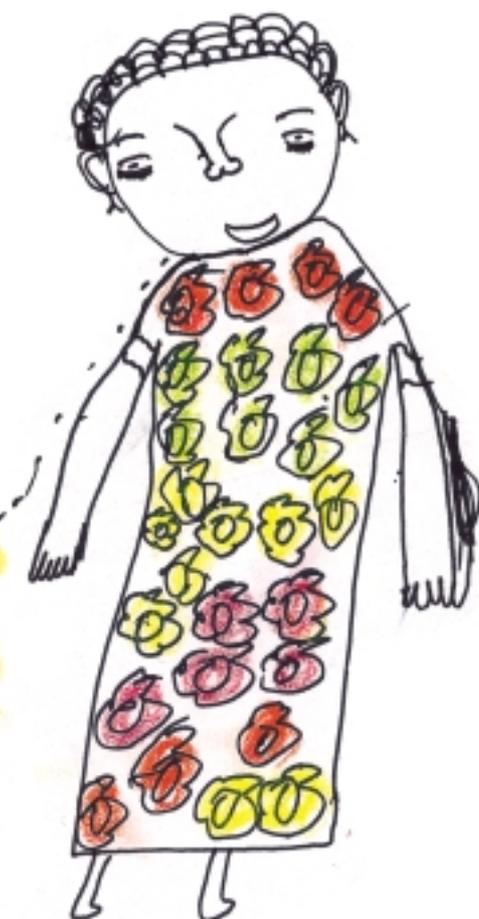
**Tiko, 13 years old:** "If you are HIV+ you make sure that you don't use others' utensils eg. cup, spoon, plate. You must have your own and put them separately"

#### 4.2.6 "Other children don't play with me"

Many of the children spoke about how their friends are forbidden to play with them because of the fact that they are HIV-affected.

**Ncobile (16 year old girl) drew this picture of herself. She wrote alongside her picture "Some people do not love me because I'm HIV"**

I have  
Some of people do not  
love me because I'm  
HIV



## “ Other mothers tell their children not to play with you. Because you’ve got AIDS. ”

**Sindile, 14 years old:** “People don’t accept you, even if you told them that you were born with it. They keep on talking about you. They have lots of things that will make you feel so small about your situation. People don’t accept these people who have HIV/AIDS - they are scared that you will infect them. Children who have HIV are always facing the challenge because parents stop their children to play with them. Children don’t understand the difference between positive and negative.”

**Tsakane, 10 years old:** “Other mothers tell their children not to play with you. Because you’ve got AIDS”.

### 4.2.7 “They call him names like skinny bones”

Each of the groups came up with a list of the names that are given to HIV+ people. Some of these are included below.

**Mduduzi, 12 years old:** “People with AIDS go shopping in a shopping centre and he sees people talking about him and calling him names like ‘Skinny Bones’ ”

**Joseph, 9 years old:** “People gossip about you. They call you different names, like 4x4, pin number or lotto”

### 4.2.8 “Talking, it heals inside”

While most of the children said that they were afraid to disclose their status, others stressed the fact that if people know your status they may help you. The following taped conversation between children (aged 10 to 13 years) captures many of the issues raised during this debate.

**Samantha:** Sometimes you have to keep your status a secret for fear of what people will say about you or do to you.

**Tiko:** The children are afraid, what will they say about us?

**Tshepiso:** The children have to keep it a secret because of the people looking at them.

**Tiko:** But I don’t think they should, because talking, it heals inside. But I suppose it depends on how bad the people are going to treat you.

**Refiloe:** Some children, when they tell the community about HIV, they don’t listen. They gossip.

**Thembisa:** Some people don’t like for you to touch them if you have HIV, even if you don’t have HIV but your parent does.

**Samantha:** Some say it’s your fault if you’re HIV+, so don’t make it our problem. They avoid you.

**Lumka:** Sometimes the neighbours speak of you when you pass by.

**Tiko:** Generally, the community says things like, you get what you deserve.

**Maria:** I think they ignore us, like when you have HIV and AIDS, they talk a lot about you. If you pass there, they say, ‘look, he’s HIV’ or whatever.

**Tiko:** They say you don’t have a future.

**Vincent:** I think they should take pains to help you, the community, especially the children.

**Tiko:** And the government must feel sorry for you and help you.

**Tshepiso:** The person who’s HIV must talk, and the more people talk, the less others can gossip. Also if the community knows, they can help to take care of you.

### 4.2.9 “Information – yes!, discrimination – no!”

On the last day of the forum, the children sang a song compiled by a 16 year old child. The song highlighted the need for information in place of discrimination. This message came across very strongly at the forum. Many of the

children felt that if people were better informed about HIV, there would be less discrimination and more openness and disclosure.

**Thalani, 14 years old:** "If we knew early about HIV/AIDS most people would not have to suffer like this. People are not open because they are scared that the community won't support them and they will blame them. If we can get support and love from each other we will succeed in the challenge of HIV/AIDS."

**Tshepiso, 13 years old:** "I think government should tell people not to keep this disease a secret, because the more you keep it a secret, the more you die."

**Tebo, 15 years old:** "People pretend that they do accept you but their actions tell you the truth. We are not allowed to touch children because we are HIV-positive, because of fear. So for our communities to accept us they still need time to be informed about HIV/AIDS."

One child's story emphasises the need for community leaders to be well informed about HIV.

**Nthabiseng, 16 years old:** "I have this father and this is his wife. These are their children. This man likes women too much. They didn't know that he is HIV positive. The bad luck came when they had a child and he was positive and that's where they started to be aware that both parents are HIV positive. This couple went to tell the chief about this situation because they live in the rural area and they don't have any experience about HIV/AIDS. The chief didn't understand he said they must leave because they are going to infect the community in his village. The chief told the people of the village to stay away from these people because they are going to get the same disease. People who are at rural areas don't have any idea about HIV/AIDS. People there are far away from clinics."

The children felt that if parents were better informed about HIV, they would be more supportive of their children. They spoke about how HIV+ children had a better chance of being accepted and supported by members of the community if their own families openly supported them.

**“ People move away from you in a taxi and they wipe the seat. ”**

**“ They think being HIV+ is the end of the world, and what I believe is that even when you are HIV+ you still have that dream that you work hard for. ”**

**Tebo, 15 years old:** "It depends whether they have information about HIV/AIDS. If they do they will always be on your side. If they don't understand anything about it, it's a big problem. I believe if my family supports me I will get support from other people. It is easy to be accepted outside when your family shows you love and respect."

#### 4.2.10. "I have been educating people"

Some of the children saw a role for themselves in educating other people about HIV.

**Delani, 16 years old:** "They laugh and when they do, it is this AIDS thing. I tell them that I do not have AIDS and that I have HIV. They tell me that they are all the same to them. Then I explain to them. There are those who used to laugh at me, who are now supported by me. I am wiping their tears now. I have been educating people. I've told them that there is no need for them to laugh at people who are HIV positive, that they should support them. Encourage them, make them happy. I've told them."

#### 4.2.11 "Teach people to fight HIV, not me."

The children had many other suggestions as to how to address discrimination against HIV-affected children.

**Tiko, 13 years old:** "I think if government allows teachers to teach us about HIV it will make the gossip less. Also allow pastors to teach and make sure the community knows everything about HIV, so that it doesn't keep happening - this gossip."

**Tebogo, 11 years old:** "Maybe there should be policeman in private clothes who hang around the place and listen to what people say to children whose parents have died of AIDS. He should arrest them."



**Tebo, 15 years old:** "Government is trying their best but is not enough because they don't reach all the people. They should teach people that having this disease does not mean that you are a different animal from them."

**Mary, 18 years old:** "I want the government to encourage equality. A person who has got AIDS needs to eat. And if you are struggling [with discrimination] you cannot eat."

**Tiko, 13 years old:** "What I think is, each and every one of us has a right. And there are only two types of people: 'affected' and 'infected', so I think HIV and AIDS is our responsibility as a nation."

**Thembisa, 13 years old:** "Teach people to fight HIV, not me."

**“ I think government should tell people not to keep this disease a secret, because the more you keep it a secret, the more you die. ”**

## 4.3 CONCLUSION

Children who are infected or affected by HIV are discriminated against at home, in schools, shops, taxis and other settings. Sometimes this discrimination borders on abuse. In some instances, HIV is seen as a punishment for being naughty or a result of being bewitched. The discrimination faced by children is often linked to the belief that HIV is spread by touching or through sharing of utensils. The children's experiences highlight the need for more HIV/AIDS awareness and education. In addition, the children asked for government to come out with a clear unambiguous message about HIV/AIDS. The children believed that by improving services for HIV+ people, more and more people would be encouraged to be tested and to disclose their status. For children living with HIV and facing discrimination on a daily basis, support groups can play an invaluable role. The children who attended the forum felt encouraged and strengthened ("talking heals") through having had the opportunity to share their own experiences and learn from the experiences of other children.