



## CHAPTER 2

# Children need help to live with HIV

HIV affects children when they are themselves infected, as is Lefa in Chapter 1, or because of how it affects their family, as in this story of a brother and 2 sisters in Zambia.

When their mother died of AIDS, Gideon was 14, Tanya was 10, and Charity was only 2. They had not seen their father much, and not at all since their mother became ill, as he was away working in the mines in South Africa. They suspected that, like their mother, he was dead too. Gideon and Tanya had left school in order to care for their mother and younger sister.

After their mother's death, distant relatives on their father's side offered to take in the girls but they were not willing to take Gideon. The children had only met these relatives once before and Gideon remembers how they refused to help his mother when she was sick. They spread rumors that she was a loose woman and most likely killed her husband by giving him AIDS or poisoning him. Gideon fears these "relatives" will work his sisters too hard and not care for them as family. He is resolved to keep the girls with him and look after them as best he can.



Gideon works as a day laborer on a nearby farm and Tanya sells extra produce they grow in their small plot. For a few seasons, Gideon had steady work and their garden prospered. They could afford to start Charity in school. But when the drought came they had little to fall back on. Like many of their neighbors, they ate less and often went to bed hungry. Charity had to stop attending school since they could not pay the fees. Gideon did what he could so Charity would have enough to eat, often going without food himself. But he worried when Charity began to lose weight.

When Charity falls ill, Gideon goes to the local food center set up to help the community in the drought's second year. The group distributes seeds and food to those in need. There, he becomes friends with Beatrice, the woman who cooks for the program. Gideon trusts Beatrice with his worries about Charity, and Beatrice tells Gideon about a government clinic that sends trained health workers once a week to do health monitoring at the center. She suggests taking his sister to see them.



Beatrice does not tell him that the health workers also test and treat people for HIV. She cannot bring herself to ask if Charity had been tested after her mother died. She suspects Gideon is secretly worried about this but isn't ready to talk about it. And she is right. Gideon fears his sister has HIV but he doesn't want to discuss it with her or anyone else. He has faced people's disapproval nearly all his life, starting when people blamed his mother for her own death and the death of his father. Thankfully, Charity does not test positive for HIV, and with more food, she gets stronger.

Over the next few months, Gideon became closer to Beatrice and her husband Charles. Charles works as a driver at the food center and he offers to teach Gideon how to drive. After Gideon gets his driver's license, he finds work at another community organization helping people with HIV. Eventually, Gideon is able to put Charity back in school. He marries his childhood sweetheart, and with the support of the local church, he and his wife are becoming admirable parents and role models. He is proud of his ability to take care of his sisters and his wife. He feels a growing sense of hope and control over events in his family's life.

Surviving children like Gideon, Tanya, Charity, and Lefa need to learn to live despite their heavy losses. Surprisingly, many do survive with remarkably strong spirits and the ability to thrive and contribute. With the help and protection of caring adults — from small, individual kindnesses to organized social programs — children infected and affected by HIV can grow up to become capable, respected members of the community. Because a child is the child of everyone, the future of these children is the future of our entire community.

All young children depend on their parents, older siblings and extended families for survival and well-being – and on their communities when families are stressed. When families go through difficult times, they often slip further into poverty and are less able to protect themselves from loss and harm. They may struggle for food, shelter, and basic resources, including time and patience to care for each other. Their children leave school, may not receive health care, and may experience abuse and violence.

## Who defends the rights of children?

While children have specific rights guaranteed by laws of their own countries and international law, because they are children they usually are not aware they have rights. Besides, young children cannot advocate for themselves. Parents, caregivers, teachers, and community leaders must make sure children's rights are respected so children are not neglected, abused, or exploited.



**Survival rights** include decent living standards, enough food, and access to health care and medicines. Survival rights focus on the child's right to live, grow, and have good physical and mental health.



**Protection rights** include keeping children free from harm, especially in difficult conditions where children may be neglected, abused or exploited. Protection rights focus on how keeping children free from violence is the responsibility of everyone in the community.

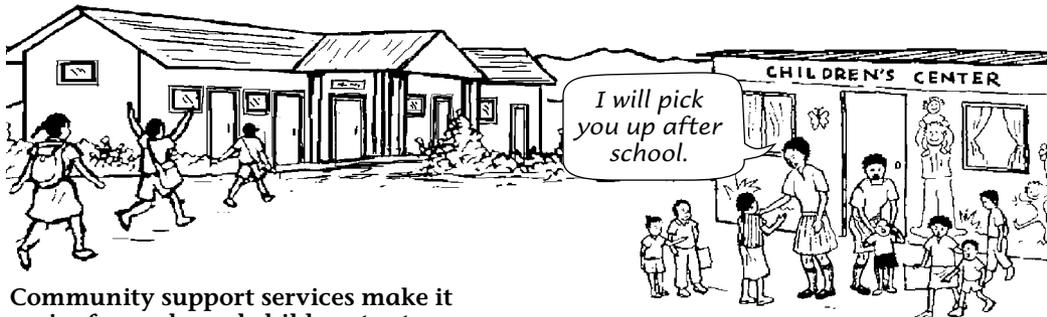
**Participation rights** include the right of children to be heard and to take part in decisions that affect their lives. Participation rights focus on recognizing that children must have a say in their lives and the life of their communities.

**Developmental rights** include the right to education, play and culture. Developmental rights focus on not just the child's survival, but on having a life worth living.

Like many rights and laws, children's rights are often little more than nice words on paper. But parents and caregivers of children with HIV are increasingly using these rights to make sure:

- children get free access to HIV medicines and needed health care.
- children who lose their parents to AIDS are kept together with their brothers and sisters and in their communities.
- families get enough food and support.
- stigma does not prevent children from getting medical care or education, and that they are not discriminated against in any way.

## Why stigma against people with HIV is so dangerous



Community support services make it easier for orphaned children to stay together in their own home.

In the years before ART treatment transformed HIV from a deadly disease to a life-long illness that can be controlled, there was a lot of fear of the disease and of the people infected with it. As more became known, many of the uncertainties about HIV illness disappeared. Unfortunately, the rumors and prejudices that had grown up around it have not disappeared so quickly. Even though it is not true, some people still think HIV spreads easily or always brings death. Their fear of illness and death causes them to isolate people who need more connection, not less, and to make life harder for people already facing many challenges. A lot of false information spreads because HIV is transmitted mostly through sex, and many people are afraid or think it is wrong to talk openly about sex and sexuality.

HIV spreads the most and does the most harm where people are too afraid to talk about what causes HIV, or to seek testing and treatment because they fear gossip, or because they worry that they and their families will be treated badly if others know they have HIV.

Children are particularly harmed by stigma. When parents delay testing or beginning treatment for fear of family or community responses to HIV, a child can sicken quickly or develop physical or mental disabilities. Children with HIV who are denied opportunities to participate in community life or schooling can develop lasting emotional problems.

That's why teaching and talking about the causes of HIV, how anyone can get it, and how to treat it are so important. When we accept that people with HIV are our relatives and neighbors, when we hear them talk about their lives and challenges, when we see them participate in community life with their talents and skills, then we see the stigma against HIV diminish.

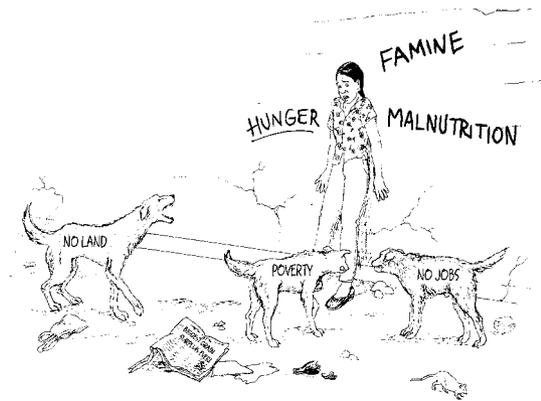
The simple truth is:

***Stigma from fear of HIV does not keep people safe from HIV, it makes HIV worse.***

## Care for children, families, and caregivers

It is hard enough to take care of a healthy child. Children demand attention, love, food, and before they can communicate well with words, you often need to be a mind-reader to know what they want.

When a child has HIV it is harder still. Children with HIV are more sickly and need more food, love, and attention if they are to grow well. They have to take medicines, which no child likes to do. They need more support to go through the same developmental changes that all children go through. All this makes the job of a caregiver harder, more stressful, and more tiring. And if a child has lost one or both parents to HIV, caregivers must also respond to the child's grief and distress.



But often the caregivers themselves are ill and need help. When there is a lot of HIV in a community, it takes a terrible toll on everyone. Adults in the prime of life, the most productive men and women in a community, are usually the most affected, leading to less income, less activity, and less energy to care for the needs of the present or to build the community's future.

In many cases, it is grandmothers who are left to care for the children because their sons and daughters are the ones who have died. Or after parents die, it is aunts and uncles or more distant relatives who take in the children, adding to difficulties they may already face in caring for their own children. In some cases, children may be left to care for themselves, the older children for their younger brothers and sisters.



For all these reasons, communities need to work together to ensure that children get the food and other care they need to be healthy, to grow up in a family that loves them, and to be able to go to school. We need to make our communities places where everyone can participate without stigma or discrimination. Strengthening ties among people will result in a stronger community. Sharing the burden of caring for children is part of caring for caregivers. It means more time and attention can be given to babies and small children so there will be fewer troubled and neglected children and adults in the community.

## Caring for caregivers

Support for caregivers living with HIV can be as simple as doing some food shopping for the family, watching the children to give a caregiver a short break, or being neighborly and helping with household chores, gardening, or a simple repair.



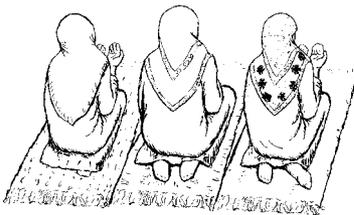
rest



massage

Parents and other caregivers will be able to look after children better if they also have some time to relax. Simple things like going to the market, visiting friends or relatives, talking with friends, having a massage, or being part of a community group can all help, especially if you feel overwhelmed.

If you care for children with HIV, you may be able to lean on your traditions to help you. Many people build inner strength and calm their minds and bodies through prayer, meditation, making art, singing, yoga, tai chi, or similar activities.



prayer



exercise or martial arts



meditation

People have found ways to cooperate to help meet each other's needs — group kitchens, support groups, shared childcare, seed-sharing, community gardens, barn-raising. Together it is possible to do what you cannot do alone.

Communities have found ways to support caregivers, which helps children. It is better to help a family feed their children, care for their health, and send children to school than to look away while the family suffers and stops being able to provide the care children need. See Chapter 15 for more information.

