

CHAPTER 15

Community support for children

To support children with HIV, support families

Families living with and affected by HIV often struggle to meet their most basic needs. But with community support, caregivers can provide the food, love, and care children affected by HIV need to grow and develop well.

In almost every chapter of this book you will find stories and examples of how communities can and do support children and families. This chapter gathers some additional ways to draw upon the strength of community to help children.

Who is your community?

Most people belong to several different kinds of communities.

One might be the people who live near you, or everyone in your village, town, or country. Another community might be members of your church, temple, or mosque.

Communities can be people who work or play together, such as members of a football team or choir, workers at a factory, sex workers, or fruit and vegetable sellers at a market. People who share similar concerns can be a community, for example, pregnant women, families with young children, people with a disability, or people living with HIV or caring for someone with HIV.

We need some people who know sign language to help at the children's ART clinic.



HIV support groups

For many people with HIV, their most important community is other people with HIV. When a person finds out he has HIV or that his child has HIV, a support group may be the first place he can find other people with whom to talk openly about HIV. People meet in support groups to talk about their shared worries, needs, and successes, which helps them trust themselves and each other. Being in a support group means you do not face your problems alone.

There is no limit to what a support group can discuss. People help each other express difficult feelings about having HIV, or decide how to tell a child he or someone else in his family has HIV. People in a support group may look out for signs of exhaustion or depression in each other, and discuss ways to relax, make needed changes, or get help. A support group can also be a place to learn how others manage HIV medicines or help children who fight too much or do not talk or play. Or people can just talk, laugh, or feel sad or strong together.

Support groups may also decide to work together to solve a problem — like starting a savings group or an HIV awareness campaign. If you cannot find a support group to join, you can start one. Often, community organizations or health centers will help you start a group or introduce you to an existing one.



Support groups can promote political action.

Community action for national change

Treatment Action Campaign (TAC) started in 1998 when a small group of activists in Cape Town, South Africa, demanded treatment for people living with HIV. Even though it was common in Europe, the US, and other Western countries, many people in South Africa did not know that medicines could treat HIV and help people live longer.

For many years, TAC organized people in support groups and local organizations through HIV education workshops, marches, protests, and legal actions to make HIV treatment more available, and to fight discrimination against people with HIV. TAC now has 16,000 members. One of TAC's first successful campaigns was to sue the government of South Africa to provide treatment for women with HIV so their babies would not be born with HIV.



Recently, TAC has begun to focus on the problems in their public health system that make treatment less accessible, such as corruption and poor management. Good guidelines and policies are not enough if the health system is broken.

Each of TAC's 200 branches across the country have adopted a clinic where members monitor services and provide support. If problems cannot be resolved locally, TAC helps raise them at the district level or higher to find a solution.





In this part of our struggle, meetings in board rooms in Geneva or New York matter less, and community meetings in Lusikisiki and Khayelitsha matter more and more.

Mobilizing your community for children's needs

Young, HIV-affected children face many serious problems — death, loss, illness, family separation, poverty, and property loss. These problems have overwhelmed too many families and left too many children not very well cared for or lacking any care at all.

When problems are so widespread and serious, it may feel like one person cannot do much. While there are always small, neighborly things one person can do, often a group of people working together can do more. And people who talk about a problem together can usually come to a deeper understanding and develop a plan of action.

Working together as a group

When you see something is needed, you can organize a way to help.

Start by involving 2 or 3 parents with children who have HIV, or concerned men and women in your church. Get whoever is interested to start working on a specific, short-term goal, such as delivering a weekly food basket to families, offering rides to a clinic, or providing a few hours of childcare each week.

By taking on and succeeding at a small project, you can show people that you are serious, that it is worth trying to improve things, and how by joining together people can make a difference. That will lead more people to take the next step or contribute to your next activity.



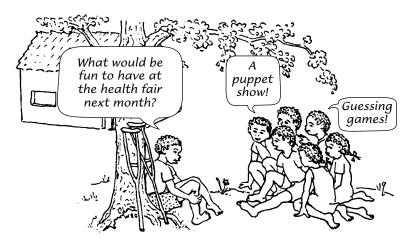


Whenever you work on problems in a community, different people will have different ideas about what is most important. It takes time and patience to involve everyone and to make them feel that their participation is valued.

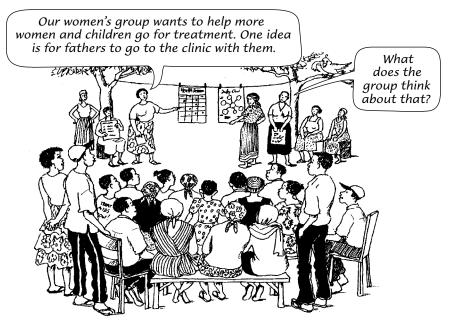
Anyone concerned about the well-being of children has something to contribute. It can be very useful to ask elders or leaders to join you as well as people who understand the problems facing children and caregivers.



Do not forget to ask children about their opinions and needs. Children often have creative ideas that can make programs more successful. Since children usually have fewer responsibilities than adults, they can bring a lot of energy to an activity.



Make sure everyone has a chance to speak at group meetings. Ask people to listen carefully to what others say. At first, women may feel more comfortable discussing problems with other women only. Then, they can share their ideas with a group of both men and women.



Pay attention to families that need extra help

Families headed by grandparents or led by older children often need extra help.



Grandmothers often need care themselves, and may lack money for orphaned children's food and other needs.



Older children who care for their younger sisters and brothers are often not ready emotionally or financially to head a family.

Support for basic needs such as food, clothing, medicine, school fees, and childcare can help these families survive. Also providing emotional support, friendship, and solidarity can help them succeed.

Help families get health care

The health system can be difficult to understand and may seem out of reach to many of the families who most need services. Caregivers who have learned how to access services can help others enroll in programs, understand HIV tests and treatment, get to a clinic regularly, and learn how to live with HIV. Training outreach workers for community HIV clinics can also help.

Mothers as mentors

Many women find out they have HIV when they become pregnant and seek prenatal care. The news can be terrifying and women can feel that they and their babies will die. Busy health workers may not have enough time to reassure and explain to these women how they can stay healthy and protect their babies from HIV. Although medicines now make it easy to prevent HIV from spreading to babies during pregnancy, many women leave the clinic after testing, too afraid to share their secret with anyone. They may never come back to get the medicine and support they need to keep themselves and their babies healthy.

A group in South Africa, mothers2mothers, trains HIV-positive mothers to support pregnant women with information, guidance, and encouragement in their own space in the clinic. They choose women who are understanding, wise, and easy

to talk to. During a 2-week training, the mothers learn about HIV and preventing infection, how to help a woman disclose her HIV to her family, nutrition, medications for HIV, and other concerns. They learn how to counsel — to talk with other women in a helpful way. These mentor mothers build upon their own experiences of being HIV positive as new mothers to support women during pregnancy, delivery, and beginning to breastfeed. They help new mothers find other needed care during the first 18 months after the birth.

You're not alone. I'm positive and my baby was born negative and healthy. Yours can be too.



Mentor mothers are paid and respected

as part of the health care team. They are role models in the clinic and also in the community. They serve for 2 years and then recruit new women to replace them from among the mothers they mentor. The experience and wages they earn as mentors have given some the boost in confidence and resources they need to start their own businesses and continue to support their families.

Help families have enough food

Adults and children with HIV need enough food to stay healthy and help their medicines work. Children with HIV really do need more food than children without HIV! Yet many families struggle for even a little to eat.

Organize a way to provide food to families who do not have enough. You might ask families to set aside a share of food each week and bring it to their place of worship or a community organization, so it can be redistributed to those in need. Or you can help a childcare center, school, or religious facility to serve a nutritious meal to children each day.



Try to help all children who need it, not only those with HIV.

- A system where only some children get help can cause resentment.
- When all children in the community eat better, they will be better able to resist other diseases as well as HIV.
- When families have enough to eat, both children and adults are less likely to do risky things for money or food, such as stealing, joining gangs, or having unsafe sex. This helps prevent HIV infection from spreading.

Giving food to hungry families helps them right away. But for people to have enough nutritious food all year round, giving food is not enough. People need places to grow food for themselves and ways to store it that protect against pests and spoiling. People also need money to buy food they cannot grow, especially in towns and cities.

Other ways communities can support better nutrition for children and families:

- Encourage women to breastfeed for up to 2 years. (See Chapter 9.)
- Help a family that is weak from illness till their soil and plant their crops.
- Organize a group of families to buy foods such as rice, beans, or wheat at a lower, bulk price. Then divide the food among the group.
- Help people start gardens in their yards or on rooftops, and reclaim land for farming in a settlement or urban neighborhood.
- Start a seed bank. People can borrow seeds and return more new seeds after the harvest.

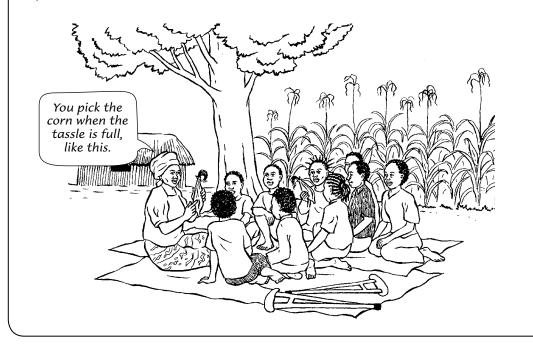


- Make high energy, Ready-to-Use foods, like "PlumpyNut," so malnourished children can benefit from them (see a recipe on page 247).
- Teach your community about the dangers of "junk food" — cakes, sweets, chips, sodas, and other sweet or salty processed foods.
 They make children feel full but provide no nutrition. Buying them means there is less money to spend on healthy foods.



Junior Farmer Field and Life Schools

In Mozambique, thousands of children have lost parents to AIDS. Many of these children live in farming communities, but now have few adults to teach them how to farm. In schools for "junior farmers," children 12 to 18 years old learn to prepare the soil, plant seeds, care for crops, harvest, and save seeds for the next crop. They also learn to care for goats, chickens, and other animals, and how to improve the soil.



For more ways to eat better when you have less money or land, also see pages 159 to 160.

Help families make ends meet

One of the biggest problems in communities affected by HIV is that so many adults have died from lack of treatment. When this happens, families lose their wage earners and farmers. These families are left without enough food or income to meet their most important needs. To help, many community projects focus on ways people can earn money.

- Give a pregnant goat to a family in need. The family can drink the goat milk and baby goats can be raised to be eaten or sold. Some families give their first baby goat to another family to share the gift. You can also give chickens, ducks, rabbits, or other animals.
- Help people grow food crops they can eat and sell, especially vegetables that produce well in a short time.
- Teach crafts such as sewing, beadwork, basketweaving, and pottery.







 Teach repair skills. TASO Uganda has an apprenticeship program for older children who have lost a parent. The children learn mechanics, hairdressing, catering, tailoring, or other skills. When they finish, they are given a set of tools to use in their new professions.

 Hire people with HIV to work in your business or agency. This fights poverty and stigma at the same time.



There are also less direct ways to help people gain more income. If you organize childcare, caregivers will have more time to work or sell things. If you make it easier for families to get water or fuel, that will free up time as well. Paying children to stay in school has been successful in Brazil.

Government aid programs

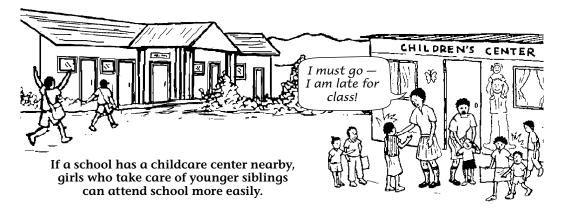
When resources such as money, land, or food are not shared fairly, the government should help the most vulnerable. Kenya, like many countries, has a government cash transfer program that gives small monthly grants to help the poorest families with orphaned children. Families who qualify can pick up their grants at their local post office every 2 months. Some people worry that people might spend the money unwisely, on alcohol, for example. But especially if the money is given to women, it helps many thousands of children eat better, get needed health care, stay in school, and lead happier, more hopeful, and more stable lives.

Help families take care of children

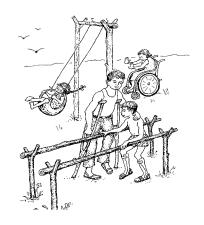
When there are not enough adults to take care of young children at home, group childcare can be a big help. While children are cared for, family members can farm, go to school, earn money, and get other things done, which helps them have more time for and patience with their children at home.

Childcare can be large or small, in its own building, in someone's house, or outside under a tree. A group of families can take turns watching all their children. Larger nursery schools can care for many children, though they need more staff to provide good, safe care. Even more caregivers are needed for children under age 2.

It is important in any childcare that caregivers understand the needs of babies and young children, including those with HIV, and know how to give them learning opportunities and help them feel loved. Experienced teachers and childcare staff often know a lot about the abilities and needs of children of different ages. They can help understand and manage problems that arise with children, and may be able to help refer to services. Childcare programs can also provide a healthy daily meal or snacks for children.



Whether children are being cared for at home or in childcare, both caregivers and children will benefit from having a common area where they can meet and play. Work with others to make a community playground, with benches and tables where caregivers can sit, talk, and watch the children, and things for children to climb, balance, or swing on. Include things that children with disabilities can use. For more about building playgrounds for all children, see Disabled Village Children, Chapter 46.



A friend to talk to when you really need it

Childline Zimbabwe has drop-in counseling centers for children and a telephone-based crisis line — the Helpline — which is available 24 hours a day, every day of the year. Trained volunteer counselors provide multi-lingual counseling in English, Shona, and Ndebele.

Children can reach the Helpline simply by calling a short-code number -116, a toll-free call. This number works from all phones operating in Zimbabwe (both landlines and cell phones). All calls to the Helpline are strictly confidential, and are usually disquised with another number on the telephone bill.

Childline provides counseling for a wide range of issues and challenges affecting children, including abuse, bullying and harrassment at school, homelessness and neglect, HIV, relationship problems with friends or caregivers, depression or thoughts of suicide, financial problems, and legal concerns.

They are part of a global network of 181 member organizations in 139 countries that supports the creation and strengthening of national toll-free child helplines worldwide.



Help families fight stigma and discrimination

Families affected by HIV are often hurt by discrimination and unkindness.

- Caregivers and children are too often teased, bullied, avoided, or gossiped about.
- Children may be refused opportunities to play with other children, to attend school, or to join clubs or sports teams.
- Orphans living with extended family may be given more work or less food than other children, or may be kept separate from the rest of the family.



• Orphans may be taken in out of obligation but strongly resented, neglected, exploited, or abused.

Trying to reduce stigma is everyone's responsibility. Children living with HIV cannot change these problems by themselves. They need adults, including their families, teachers, and community and religious leaders, to protect them and set better examples. Stigma can also affect families with HIV by isolating them in the community, causing problems with jobs or income, or denying them opportunities that others receive. This affects their children too.

It is our responsibility to speak out against all these kinds of stigma, to stand up for ourselves and each other, and for children affected by HIV, to accept people with HIV into our lives, businesses, and places of worship, and to help all children be treated kindly and fairly.



Educate others

Dealing with prejudice and discrimination is frustrating, upsetting, and hurtful. It can make you angry and down-hearted. If community members are afraid to be with people affected by HIV, try to remember that this comes from their fear and misunderstandings. Explain this to them and to your children.

Knowing the facts about how HIV does and does not spread (see Chapter 1) can give you strength and help you educate others. Work with others to confront and educate your community. Do not accept being treated badly.

You cannot get AIDS from shaking hands! I cannot believe Living with HIV you shook her is not easy. That hand! Her whole family, and that girl family has AIDS! are not strangers. Let me tell you the truth about HIV...

Share your story

One of the most powerful ways to break the stigma of HIV is to show how all kinds of people are affected by HIV and what HIV means for them. This might include sharing your own story about HIV by telling people in a public way that you have HIV, and what it is like to live with HIV or to raise children with HIV. This may not be easy, but it is very important.

Because people with HIV are often rejected, many keep their HIV a secret. Speaking out about your HIV can help you and other people with HIV feel less alone. When people who do not have HIV hear your story, they may learn to be more compassionate. They may be inspired by your bravery. This builds solidarity between people with HIV and those without it.

You may decide to share your story at a community event or by writing to a newspaper, talking on the radio, or speaking at your church. You may share your story at the same time that others do.

Deciding to share your story publicly is a big decision. Talk with trusted friends, family, or an HIV counselor about how it could affect you and your family. Sometimes people wait to share their story until after they have been living positively for awhile and can share that part of the story. Others feel more comfortable speaking outside their community, but avoid discussing their HIV — and facing discrimination — at home. Only you will know if, when, how, and with whom you are ready to share your story.

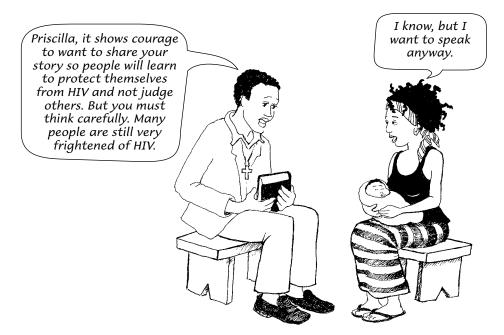
Priscilla's story

When I was 15, I had a relationship with an older man in my town. He gave me a cell phone, money for food, and paid my school fees. I kept him company and had sex with him when he wanted.

When I was 16, I discovered I was pregnant. I went to the clinic and they told me I had HIV. They also told me that I could help keep my baby well by starting on medicines right away. I thought about my cousin with HIV who tried to hide it. When she got pregnant she never went to the clinic and never took medicine. Her baby is always sick, and I think maybe that baby has HIV too. So I decided to take the medicine and keep going to the clinic.

Now my baby is 8 months old, and still HIV negative. It was hard to face my HIV but this baby has made it worth it! I want to help other mothers learn how to protect their babies.

One Sunday, I stayed after church to speak with my pastor. I have known him since I was a child and I trust him completely. I told him my story and said I wanted to share it with the whole congregation, to help them know more about HIV and be less afraid.



The next week, the pastor invited me to the front of the church as he finished his sermon. I was nervous, but I told myself to be brave.



When I finished, everyone stood to clap for me! I was surprised. Happy and surprised. After the service, 2 young women came up to me and thanked me for speaking.

They told me that they too both tested positive for HIV but had not told anyone but each other. Hearing my story made them feel stronger and hopeful. I was so happy.

Walking home, I was thinking about the service when a car drove by. A boy yelled out the window that I should die of AIDS and threw some garbage at me. I was shocked, afraid, and hurt. I cried a little when I got home. But I told myself that even if some people are unkind and do not understand HIV, I will keep speaking out so more people will learn what it takes to stay healthy.

Reducing the stigma of HIV helps all of us

Anyone can become infected with HIV, and stigma against people with HIV helps HIV spread more easily. Stigma about HIV causes people to:

- avoid talking about HIV with their sexual partners.
- wait until they are very ill to be tested for HIV.
- hide their HIV status.
- avoid taking ART medicines, or miss doses, for fear that someone might see them.

All of this spreads HIV.

There is no good reason to avoid people with HIV — HIV does not spread through casual contact. When we treat people with an illness like HIV (or those with cancer or disabilities) as though they are damaged, contagious, dangerous, or wicked, we are acting as though they are not people just like us. But HIV can happen to anyone! And if it does happen to you, you will be deserving of respect and kindness.

Using media, arts, and events in the community

Public media, such as newspapers and magazines, television, radio, and videos, billboards and posters, theater, creative arts, and social media can all help change how people think about HIV, get the word out about your activities, and build community support for children and families with HIV.

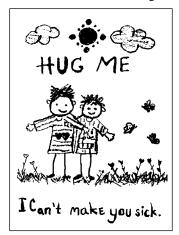
Creating a media campaign

- To create a message, think about the most important things you want to say. Be creative

 how can you get people's attention and make them think?
- 2. Next, decide on the best way to share your message with the community:

 Approximants on the radio? Advertisements

Announcements on the radio? Advertisements in newspapers? Performances in parks or markets? Pamphlets in health clinics? Talks at schools or churches? Posters in schools, community centers, or markets?





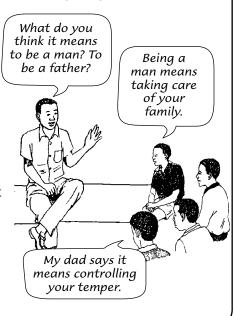
3. Think about your resources. Can someone help you make posters? Will a radio station give you free airtime for announcements? Would someone at the local newspaper write an article about your activities? What methods will work well to share your message?

Banners and posters in marches and at events are media you control.



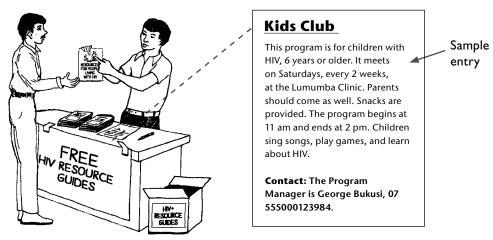
The MenCare South Africa program at Sonke Gender Justice helps men better participate in raising their children, from the moment they are born.

The campaign profiles active fathers on the radio. Children and other community members nominate fathers by telling their stories, which are recorded for broadcast. Sonke also organizes support groups for fathers to come together to share ideas about parenting and to discuss the challenges of raising children, including those affected by HIV. Fathers then take these messages to schools where they talk with young people about the importance of caring for children and how to be a good father.



Make a resource guide

Especially useful in cities, a community resource guide lists services, programs, and organizations that can help people with various needs or problems. For example, a resource guide for children might include schools, child services, and youth programs in the community, with short descriptions of each one, phone numbers, and how to find them. You can give copies of the finished guide to schools, clinics, or shops, or hand them out at markets, meetings, and events. Maybe a local business will fund the production cost.



Art projects create and educate the community and support mental health

Traveling theater

In Thailand, health educators go all around the countryside to teach about HIV and AIDS. They perform plays in the street and at markets, schools, and temples. After the play, the viewers talk and the group offers prevention counseling and gives away condoms.



Dance parties, football matches, street fairs — all can be occasions to share information about HIV. A local clinic could provide HIV testing, treatment information, or weigh children. Give away condoms and recruit volunteer home visitors and community gardeners.



Body maps are outlines of a person's body, whether an adult or a child. The person fills in the outline with colors or pictures that show how they feel when they are ill, or what makes them strong inside and able to fight HIV, or anything else that shows who they are. Exhibits of body maps can show others how people with HIV are more than their HIV.

A mural can bring community members together to discuss what their community used to be like, the problems it faces, and how they would like it to be. Everyone can help with ideas, how to show them in images, and (the best part) painting together. A completed mural serves as a brightly colored reminder of how people can work together to build a future for the community's children.



The outside is what everyone sees. But you can show the inside or not. You can put things inside and not think about them for awhile, like bad memories.



A suitcase project can help children who have lost their families and moved far from their homes. Children make art on old suitcases to tell their stories, their lives now, their past, their journey from where they lived before, and where they will go in the future. Over many weeks, they paint, print, and draw, and sometimes talk, and then they layer beads, sand, shells or other objects on their drawings, and attach them all on their suitcase.

World AIDS Day

World AIDS Day is December 1 every year. People all over the world talk about HIV and AIDS, remember those who have died, and celebrate the survival and contributions of those still living with HIV. People offer HIV testing in the community, teach people facts about HIV, and work against stigma. Participate in an event in your community or organize one. Even if it starts small, it will grow larger every year.



The town of Kisumu, Kenya, holds a race every year on World AIDS Day. Local organizations share information about HIV and provide HIV counseling and testing. The money they raise from the runners' registration fees helps fund schooling, food, and other needs for over 300 children orphaned by AIDS.

How to find resources

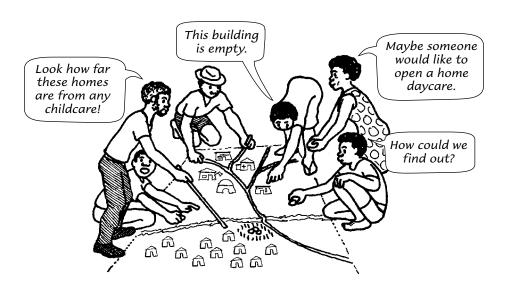
When you decide to work on a problem, try to find out if other groups or services already exist to help with the problem. For example, if you and a neighbor worry about women with HIV raising children alone, you could ask at the clinic and other HIV counseling sites about support groups for HIV-positive mothers. Also ask about AIDS support organizations or child welfare committees. If these exist, then you might decide to work with them to help meet more of the women's needs. This is easier than starting a new project, and the group should welcome your new energy and enthusiasm.

Community mapping

Mapping is a way to organize information about your community and help you decide next steps for action. Gather a group. Draw a large map of your village, town, or neighborhood on a blackboard, on the ground, or on a big piece of paper. A simple map of roads, paths, and main buildings is fine.

Ask people to mark on the map all of the services they know of that are related to your problem, for example, the clinic that helps people with HIV, or childcare programs for HIV-positive children. You will be amazed at how much your group already knows! You can probably add to your map by asking workers at a hospital, clinic, or community organization about other resources.

You can also use this map to identify problems — where services are lacking and who is well-located to help provide them. Knowing where different kinds of help are needed and what is most urgent can help you figure out how to work on making it available.



Here are some other ideas for how to raise support:

> • Ask people to contribute time and skills.



· Get local businesses and government officials to donate food or a place to meet.



Our mothers group needs a meeting space. May we use an empty office on the weekend?



• Sell goods.



• Organize community members to work together on a project.

Digging a new well is a good idea. There will be less sickness for everyone, especially children.



Making families stronger

Communities in KwaZulu-Natal, South Africa, have worked for better jobs, safe water, enough food, and access to electricity for a long time. But when HIV and AIDS came, many people died. A great many children were left without parents to care for them. Community members knew something needed to be done to help these children.

In response, a group named Thandanani (which means "love one another") began organizing community-based, volunteer, childcare committees. Members went to local hospitals and communities to find children who had been abandoned or whose parents had died. They provided resources these children needed, such as food and clothes, and looked for foster families for the children. They found families who were willing to provide orphaned children with the love and care they needed.

As they did this, Thandanani discovered how many families needed ongoing support to be able to care for the children they took in. The poorest families often needed emergency help just to have any food. Others needed emotional support, help getting services or identity documents for children, or better access to health care. Thandanani helped in all these ways and more. The people working most closely with families were from the community, so they understood the challenges families faced and also how capable and resourceful they could be. Thandanani strives to empower families, to provide support while also helping people think about how to solve their problems themselves.



As a fieldworker with Thandanani, I learned a lot of new skills. But no one had to teach me to love the children in my community!



Many years later, Thandanani has grown bigger and stronger. Now, instead of forming volunteer committees, they hire and train people from the local community to be Thandanani fieldworkers. These fieldworkers still provide a wide range of support to foster families caring for orphaned and abandoned children. They work with families for 3 years, with the goals that:

- caregivers will be able to provide loving care and protection for children.
- · children will have enough food and clothing.
- children will go to school and learn and grow well.

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