



THE BRAVEST BOY I KNOW

A UNAIDS publication with pictures by Sujean Rim
Discussion guide





Summary of the book

The book features two delightful eight-year-olds living in Africa: a girl called Kayla and a boy called Kendi. Kendi is living with HIV, but seems as happy as any other child. The story focuses on their carefree life at school, at home and in the countryside. The book also discusses Kendi's feelings about being unwell sometimes, and about his mum's support when he takes medicine. Kendi is full of dreams and imagination, and has worked out how to deal with the challenges that come with living with HIV. And Kayla adores him, describing him as the "Bravest boy I know".

This little book is deliberately light, friendly and positive. It may be useful as a discussion starter for many audiences, especially children aged five years and over, including children living with HIV, parents, other family members, caregivers and friends, as well as health-care providers, teachers and other support professionals.

What is HIV and how do children acquire it? HIV stands for "human immunodeficiency virus", and is the virus that causes AIDS. AIDS stands for "acquired immunodeficiency syndrome". More than 1.8 million [1.5 million–2.0 million] children are living with HIV like Kendi, and most acquired it from their mothers during pregnancy, delivery or breastfeeding. Without medical intervention, children born of mothers who are living with HIV have a 15–45% chance of acquiring HIV, but with intervention the chance is reduced to 5% or less, especially if the expectant woman was already on antiretroviral therapy at conception, which has been shown to suppress transmission before six weeks even further, to close to 0.2%. HIV infection is more aggressive among children, due to their immature physiological development, especially their weaker immune systems. Therefore, without treatment, half of children living with HIV are likely to die by the age of two.

What are the most recent developments about HIV and children?

In 2011, world leaders came together and committed to change the trajectory of HIV among children. Special focus was put on the 21 countries¹ where 90% of HIV-positive pregnant women live. The aim was to reduce the number of new HIV infections among children by 90% before the end of 2015. They also committed to reducing deaths among pregnant women and children due to AIDS-related illness by 50% within the same time period. The initiative, branded as the *Global Plan towards the elimination of new HIV infections among children by 2015 and keeping their mothers alive*, ended in 2015 with encouraging results. There has been rapid momentum in scaling up access to HIV prevention and treatment services for

¹ Angola, Botswana, Burundi, Cameroon, Chad, Côte d'Ivoire, Democratic Republic of the Congo, Ethiopia, Ghana, India, Kenya, Lesotho, Malawi, Mozambique, Namibia, Nigeria, South Africa, Uganda, the United Republic of Tanzania, Swaziland, Zambia and Zimbabwe.



women and children. As a result, there was a 60% reduction in new HIV infections among children between 2009 and 2015 in the 21 priority countries in Africa. There was also a 62% reduction in AIDS-related deaths among children under 15 years of age. Some countries, such as Burundi, South Africa, Mozambique and Uganda, have reduced paediatric AIDS-related deaths by 80% or more.

What are the challenges?

While a lot of progress has been made, success is still not 100% and some children like Kendi acquire HIV. In 2015, globally, around 150 000 [110 000–190 000] children under 15 years old contracted HIV. Globally in 2015 there were a total of 1.8 million [1.5 million–2.0 million] children under 15 years old living with the virus. Children living with HIV need support and action. They need to receive care and treatment, and their parents also need support.

How can children deal with HIV?

Fortunately, science has made rapid progress over the past few years. However, treatment for children is expanding much less rapidly than for adults. In 2015, the World Health Organization (WHO) issued new recommendations outlining how children living with HIV can benefit most from antiretroviral treatment.

The 2015 WHO guidelines recommend that all children be offered treatment immediately upon diagnosis—although the IeDE research consortium estimates that children do not begin treatment until a mean age of of 3.8 years—and that all pregnant women be offered antiretroviral medicines and counselling, for their own health and to reduce the risk of transmission to the child. These guidelines are designed to simplify treatment and bring HIV care closer to the patient and into the community.

There is still no cure for HIV, but antiretroviral treatment slows down the progression of the virus in children. Parents like Kendi's mum, and other caregivers, should seek the advice of health-care providers on how to support children living with HIV.

How to manage treatment for children

Since no one medicine can suppress HIV alone, children will take several medicines every day once treatment starts. For the smallest infants, the medicine may come in the form of syrups, for the child to take at home. Recently, the United States Food and Drug Administration approved a new pellet-based paediatric medicine formulation suitable for infants just months old. This formulation is being piloted in several countries in order to determine how mothers and caregivers can deliver it for optimal impact. It is best to discuss with health-care

providers how to manage the situation with schools and other family members. Health-care providers can also advise on when to inform children that they have HIV, and when to inform others, such as teachers. In some cases, children may have side-effects and may feel sleepy or vomit or have muscle aches or other discomfort. It is best to help children feel free and comfortable enough to tell a trusted adult when they have concerns.

How can this book be used?

This book can be used to help people understand HIV among children and especially to understand that children bounce back and do well when on treatment. HIV-positive children can go to school, play and live like any other children. They, and their families, need care and support, not stigma and discrimination.

For parents, caregivers, teachers and health-care providers: if a child has acquired HIV, you can take comfort in knowing that there is hope. Treatment is now available and it means that children can survive and thrive. There are many adults alive today who became infected with HIV at birth and have grown into adulthood. People living with HIV can enjoy a better quality of life because of new HIV medicines, better care and more support.

For more information please see the following:

UNICEF. HIV and children. http://www.unicef.org/aids/index_action.html.

World Health Organization. Treatment of children living with HIV.
<http://www.who.int/hiv/topics/paediatric/en/>.

World Health Organization. Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection. <http://www.who.int/hiv/pub/arv/policy-brief-arv-2015/en/>.

Elizabeth Glaser Pediatric AIDS Foundation. <http://www.pedaids.org/>.

Your ministry of health officials or health-care provider.

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