

The Meaningful Involvement of Children Living with HIV



A united response
to a global challenge

BACKGROUND

Why is the meaningful involvement of children living with HIV important?

About two million children under the age of 15 were living with HIV in 2007. There is no accurate data about the number of young men and women aged 15-18 years. However, the numbers of HIV-positive young women in antenatal clinics are extremely high in this age group. In some parts of Africa up to two to three times, even four times, as many young women as young men are HIV positive.

1. There has been not enough focus on children's treatment needs; children living with HIV are powerful advocates for treatment.

Many children are born with HIV, because their mothers do not have access to treatment that could reduce the risk of HIV transmission. Many HIV-positive mothers do not get access to treatment themselves. Each day, some 1500 children under 15 years of age become infected with HIV, an estimated 90% of whom live in sub-Saharan Africa. Many more children get HIV during their childhood – from unprotected sex, which is often forced, from unsafe blood or from injecting drug use and sex.

Most HIV prevention programmes assume that children do not have HIV and are not at risk of infection when young; the information that they provide does not meet children's reality.

Access to testing for pregnant women and babies is still not reaching the women that it needs to. Only one third of HIV-positive pregnant women are accessing drugs to reduce the risk of infection to children worldwide. Children born with HIV are more likely to get sick quickly and it is harder to test for the HIV virus than in adults. AIDS has become one of the major killers of young children. One in seven people dying of HIV-related illness worldwide is a child under 15 years old and at least half of all children born with HIV die before they reach the age of two years old. Yet paediatric HIV is almost entirely preventable with effective HIV prevention, testing and treatment. In rich countries, mother-to-child transmission rates are less than 2% and most children with HIV live past the age of six and more.

Treatment for children remains more expensive and less accessible. The drugs need to be produced in different size doses than adults; and in syrup form for babies and infants. This is often not available.

2. Children are often not given the same 'rights' as adults, even those living with HIV, including the right of access to information about HIV and sexual transmission.

Many children living with HIV struggle because their parents or guardians do not give them the information – even the facts about their own HIV infection – or space to make their own choices. Many children living with HIV are not told of their HIV status for a long time. This makes it hard for them to make decisions about their treatment and other aspects of their life.

Children are sexual beings and need access to age-appropriate information about sex, including HIV transmission and other sexual and reproductive health issues. HIV-positive children are often not given appropriate information about HIV transmission and their right to make healthy sexual choices.

Discrimination can lead to children being thrown out of school; or being put into prison, for example if they are sex workers or injecting drug users. Laws protecting children are different to those protecting adults, for instance on inheritance, rights to information and rights to make choices about where to live and who to live with.



3. Children are not ‘young adults’: policies on the meaningful involvement of children rarely look at the particular needs that children face.

Although there are some excellent policies on the Meaningful Involvement of People Living with HIV, few of the policies or programmes have made efforts to include children and young people. Children face particular issues that adults do not face (such as going to school, the need for sexual education in preparation for becoming sexually active, future life choices). Information needs – for example, about treatment – are different than adults or may need to be provided in different ways. Children’s legal situation is different; they often have other people making choices for them, about treatment or about where they live and who they live with, especially if they have lost their mother.

4. Girls are especially vulnerable to exposure to HIV as teenagers.

In high prevalence countries, up to five or six times as many girls aged 15-19 years have HIV compared to boys the same age. Girls are more likely to be taken out of school than boys, sexual relationships with older men are often an economic necessity or are forced. Gender inequalities are pervasive in youth and childhood, yet there is not enough focus on the different needs of young women/girls, and young men/boys.

Some young boys are especially vulnerable. Boys and young men who have sex with boys or men, whether by choice or forced, will rarely have a safe space to get information on their sexual health and HIV needs.

CASE STUDIES

Examples of how the meaningful involvement of children living with HIV have made change to people’s lives.



Memory books and Hero books. Giving children a voice.

There are some tools that help children tell their stories. In Southern Africa, children use tools such as Hero Books to name the challenges that they face in life. A “hero book” – written and drawn by the child or young person him or herself – can help set goals, and give them power over a specific challenge or obstacle in their life. Memory Phiri is one of a team of child trainers who are now working with other children to support them to tell their story. Hers is a story about refusing to be a victim and about helping others to change their own prejudice and stigma.

When her parents were alive she thought life would carry on just fine. Then her parents died and no close relative was able to take her and her young brothers in. They were hungry and taken to different orphanages across Zambia. She felt safer in her new home but there were problems to overcome. She overheard whispers and gossip about herself. On the wall outside the classroom, someone scribbled: “MEMORY PHIRI HAS AIDS.” She wrote her story book – the problem became a creature called Chikonko, who represents stigma.

She took a courageous step and talked to the girls in the orphanage about her story. She told them that at thirteen, she had been raped because her parents had both died and there had been no one to protect her. She told the other girls that all the shame and blame belongs, not with her, but with the man who raped her and who infected her with HIV. When she told this story, the girls listened and many of them wept. The school bully apologised for all the teasing. This was Memory’s shining moment.

“I have found people I can trust and sharing with them my feelings I have overcome my fears and become more focussed in life... As a result of their speaking for me and my own speaking out for myself people now just see me as Memory and not that girl who will die soon.”

Memory is now a trainer in hero books. She helps other children speak out about their stories. She also earns money now by being paid a proper rate when she trains and now is bringing up her younger brothers.



Speaking out on children's right to treatment

Children can be powerful advocates for treatment. Saranya is 12 years old and she is a member of the Children's Unit of Positive Women's Network in India. She says *"Adults don't have enough understanding on children issues. This adult doesn't have a conversation with children about their problems and can't give solutions. For us, the most important things are getting right information, being treated equally with all both infected and affected. If children are positive, adults don't make them get educated. Already girls don't have higher education, if they are positive, the parents neglected to send them to schools, and boys are mostly send them to labour and not for studying."* Saranya has spoken out clearly and confidently, in front of senior political leaders, on the right of children to have access to paediatric treatment.



Teen Spirit

Teen Spirit is the UK's only support group for teenagers aged 13-19 who know how HIV affects their lives. The project provides a safe, supportive, caring and educationally stimulating environment where young people living with or affected by HIV can build up vital support networks; be encouraged to develop skills confidence, and positive self identity; be encouraged to learn, develop and realise their own potential; and maintain health and well being. What is important is that it provides a service that that young people can access independently of an adult, which is especially important if a caregiver is unwell, or has died.

Young people are actively involved in Teen Spirit & Body & Soul. This includes planning and delivering workshops and seminars, working as peer mentors and treatment advocates, designing new projects to meet the needs of young people, doing outreach through talks, training, media and sitting on the Trustee board.

The organisation had to make some changes to their ideas in order for young people to be meaningfully involved in decision-making. For example, the organisation does not have a single standing steering group with fixed membership / representation of young people. Feedback sessions are held four times a year which offer a formal space where they can comment on the programmes and workshops that have been available to them over the previous 12 weeks. They can identify

activities that they felt worked well or less well and they can identify themes and activities they would like support with in the future.

Body & Soul has two young people representatives on its trustee board. Sarah is 24 and joined Body & Soul when she was 14. She was an active member of the Teen Spirit group and now volunteers on a regular basis with Teen Spirit. She provides regular telephone support to those teenagers who are unable to access the centre directly on an ongoing basis, such as those that live outside of London. Sarah was recently joined on the Trustee Board by Jo, who is also 24 and has been attending Body & Soul since she was 16 yrs old. During this time Jo has consistently spoken up on issues affecting young people living with HIV. She has had to overcome many challenges, from the loss of mobility to more recently losing her sight. Throughout this, she has been an inspirational member of Body & Soul.

Other examples of how they got involved include a Teen Spirit evening dedicated to 'campaigning', in which young people identified preferred themes and mechanisms to achieve the message they wanted to communicate. They decided on 'a smile is a gift' campaign led by young people at Body & Soul. The campaign achieved a lot of media attention and resulted in a parliamentary event; a high profile public event in London and an increased awareness on issues affecting young people living with HIV in the UK. Body & Soul won the Youth Action Network Makin' it Real Award 2007 for increasing awareness of HIV. Members of Teen Spirit spoke at a range of public events including a reception held at 10 Downing Street with Gordon Brown. They made the prevalence of HIV in the UK 'real' by sharing their personal stories, their struggles and challenges in front of corporate business people, MPs and health ministers. Other recognition includes two members receiving The Diana Award for volunteering in July 2008. Both members who received the award are volunteers in the BaSe service for 10-12 year olds, and are dedicated, committed role models for the younger children.

RECOMMENDATIONS

What can we do to promote the meaningful participation of children living with HIV?

All organisations working directly with children living with HIV should...

1. Support children by providing the information and space to speak out for themselves

Ensure that your programme is a safe place for all children to be when they do speak out. Make sure that all procedures such as confidentiality have been designed with children's input. Make sure that your organisation has a proper child protection policy in place.

- Be open and honest with the children who are part of your organisation. Children are often not given information or are not allowed to ask questions. Information is powerful and gives confidence to speak out.
- Be aware that many of the children living with HIV have experienced loss and may have many other emotional concerns. Provide counselling and other support to the children if they want it, by people who are experienced in child counselling. Be aware of the need for counselling and support on sexual abuse and violence, for both boys and girls.
- Children need time to participate. Many children are busy going to school, many more are busy working or caring for younger brothers and sisters or a sick or frail parent or grandparent. Children who are orphans may be especially hard worked. Make sure that the time that children put into participation is compensated.
- Have mechanisms so that other children who are not part of the organisation can give their input before and after decisions are taken, without expecting them to be part of an official board.
- Give children the resources and space to organise themselves.
- Ask children living with HIV when and how they want to be involved as 'children living with HIV' and when and how they can be given time as boys and girls without being given special treatment. This might be working with children living with HIV within a broader child or youth programme, or linking with local youth groups.
- Consider what children on treatment may need – for example, if children are taking medicines at a fixed time, arrange the activities around this so that children do not forget or feel that they have to interrupt the activity to take their medicines.

2. Give children and young people of all ages the space to make their own decisions and run organisations in their own way.

Girls and boys of different ages have different interests and ways of organising themselves. The best way to find out is asking children themselves in peer groups. For example, 6-8 year olds, 8-12 year olds, 12-16 and 16 years upwards. Children will know which groups they feel free to be in. Provide adult support when the children's group wants it, such as to help them decide how to organise themselves, to give information or assist in planning activities.

3. Make sure that it is as easy for girls to participate as boys.

Does your organisation support mentoring programmes for girls living with HIV? Children living with disabilities face a double burden when they also have HIV (and HIV infections are often high amongst disabled people because of insufficient information and discrimination.) Is your programme accessible to disabled children?

4. Work with children's caregivers and other significant adults, as well as with the children themselves.

Many children live in families and have adults who are caring for them. These adults often find it hard to talk about HIV and other complicated issues with children. Children need support at home if they are to be involved. Can your organisation provide support and training for the caregivers? Are there organisations of people living with HIV who can work with caregivers to help them communicate with their children?

"The memory book has helped us in being open to talk to children at home or for example if there is an illness or a funeral at home to be able to tell the children. Normally we adults like to hide as we tell the children when there is a funeral that your mother or father has gone somewhere."

Knox Zimba, Zambia.

5. Make sure that children have access to quality health care so that children living with HIV remain well.

NGOs need to make links with health care providers so that children, and their mothers when their mothers also have HIV, can have quality access to treatment, including prevention of opportunistic infections, and they can stay healthy and active.

Many children find it hard to access confidential and non-judgemental services, especially that relate to sexual health. Make sure that these services are available, either yourself or by working with local health workers who you trust.

HIV advocacy organisations, especially those led by people living with HIV should...

6. Systematically include the rights of children living with HIV, and their particular needs, in advocacy activities

All too often, global or national declarations on the rights of men and women living with HIV have not looked at the particular rights of boys and girls living with HIV. Networks such as GNP+ and ICW, and other regional and national networks, can ensure that children living with HIV are consulted on and included in advocacy work. For example, children's treatment needs vary from those of adults and so advocacy recommendations need to be adapted to children's needs.

7. Document and provide guidance on the meaningful involvement of children living with HIV

Currently there is limited experience of how to mainstream the experience and expertise of children living with HIV into policy and programme development. Global policy groups, such as UNAIDS or the InterAgency Task Team on Children and AIDS, in partnership with PLHIV networks, should consolidate current experience and provide more detailed guidelines in this area.

8. Ensure that children living with HIV participate in governance and management structures directly or in partnership with children's organisations

Often it is difficult for children to participate in national or global advocacy structures that are led by adults. Proposals for facilitating the most effective meaningful involvement of children should be shared with local members who are already run by children or have children's meaningful input. These organisations can assist in the design of and monitoring of a children's involvement process.

9. Organisations that are led by, or have meaningful leadership of, people living with HIV should partner with global children's advocacy movements to ensure the meaningful involvement of children living with HIV in their children's processes.

Organisations such as GNP+ or ICW, or others advocating for MIPA, should ensure that children's organisations such as Global Movement for Children or UNICEF-supported programmes should ensure that children living with HIV are actively included in their child participation activities.

What are children's advocacy messages?

Supporting children's meaningful involvement in your organisation is the most important starting point for advocacy by children living with HIV. Children will identify their own messages and priorities. Below are some of the key advocacy issues that HIV-positive children have identified.

- Children have a right to HIV treatment. This means advocating for early HIV testing for children as well as mothers and for access to paediatric and child formula ART.
- Children's parents and caregivers need access to information about HIV, and to HIV treatment when they have HIV themselves.
- HIV-positive girls and boys have a right to know their HIV status and understand about their health, through supportive and confidential services.
- HIV-positive children have a right to information about growing up, including the right to know about their bodies, make choices including sexual choices and be supported in those choices. This includes making sure that HIV prevention programmes consider children living with HIV as well as those that are uninfected or do not know their status.
- When children living with HIV may suffer a lot of stigma from peers at school or at home, their right to confidentiality and right to support when choosing how to disclose.
- The right to quality education and lifeskills – the right to have the same choices about future life (relationships, friendships, work options) that all children have.



Where you can go for further information

Organisations of children and young people living with HIV:

Currently there are no global organisations of children living with HIV. There are many smaller groups at local level. For more information on possible local groups, contact:

- AIDS Alliance for Children, Youth and Families in North America works with HIV-positive children and youth, supporting their participation in their own groups and broader advocacy. www.aids-alliance.org
- Asia Pacific Network of People Living with HIV has some national members with children and youth groups. www.apnplus.org
- Global Network of People Living with HIV works with PLHIV networks across the world, some of whom are led by youth and many of whom include children. www.gnplplus.org
- Global Youth Coalition on HIV/AIDS hosts Living Positively, a network of young people living with HIV which has carried out many advocacy activities and works with Hopes Voice International which is a global network of HIV-positive youth advocates. www.youthaidscoalition.org and www.hopesvoice.org
- International Community of Women Living with HIV has worked with girls and young women and has national and regional representatives in every continent. www.icw.org
- The Regional Interagency Task Team on Children and AIDS (RIATT) in East and Southern Africa recently had a children's conference in Africa at which many HIV-positive children and young people attended. Details currently not available but will be posted on www.unicef.org
- Young Women's Christian Association has worked with many groups of young women, many of whom are positive. www.worldywca.info

Resources

Children's meaningful involvement

- *Child and Youth Participation Resource Guide* includes many organisations working on children's participation, including those working on HIV. www.unicef.org
- *Children as Active Citizens: Commitments and obligations for Children's Civil Rights and Civic Engagement in East Asia and the Pacific* gives programming and policy guidelines on meaningful involvement of all children, not HIV specific. Inter Agency Working Group on Children's Participation, 2008, www.iawgcp.com
- *Mobilising Children & Youth into their Own Child- & Youth-led Organisations* gives lessons from a Tanzanian child-led group of children affected by HIV. By Kurt Madoerin, REPSI, 2008, www.repsi.org

Children living with HIV

- *Kids ART Education Series* is a series of booklets and resources, such as games, stickers and advocacy posters about HIV and ART. It is designed for children aged 6-12 to share with their peers and adults, for caregivers who are helping children with adherence and for adults to understand the issues children on ART are facing. SFAIDS, July 2008, info@safaids.org.zw www.safaids.org.zw

There are few written or filmed resources about the meaningful involvement of children living with HIV that are available globally, although children and young people have contributed to many publications.

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