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Children should be seen as active citizens with distinct roles and abilities.

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The different experiences of girls and boys of different ages need to be understood.

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Introduction

This paper looks at the involvement of children, including young children, in responses to HIV and AIDS and examines issues around children’s participation. It explores the challenges of enabling children to express their views and priorities effectively and suggests how they can best be supported through a range of appropriate media and communication approaches. The paper draws on the experiences of people living in communities affected by poverty and HIV and AIDS, and highlights examples of initiatives that successfully involve children.

Key points

- The specific needs and communication styles of children of different ages need to be recognised and accommodated in responses to HIV and AIDS. Methods that support children to express themselves and communicate effectively need to be documented and more widely shared.
- There is a need to build on the documented success in involving children in decisions that affect their lives, to give them the tools and space to participate effectively in responses to HIV and AIDS.
- The different ‘childhoods’ and experiences of HIV and AIDS, poverty, and of participation for girls and boys of different ages need to be better understood as the starting point for interventions with children.
- Meaningful involvement of children in responses to HIV and AIDS requires significant investment of time and resources over the long term.
- There is a need to address barriers preventing children’s involvement, such as scarce time and resources and differences of confidence and power between children. Efforts to involve children also need to be sensitive to the household and community context, and engage communities in addressing harmful local cultural norms and practices.
- In order to assess its effectiveness, the scope and quality of children’s participation in HIV and AIDS initiatives need to be clearly defined – including in relation to differences of age, gender and diversity.
- Child- and youth-led organisations and networks need to be supported, both to further children’s ability to secure their rights and to support children’s public engagement and social awareness.

1 The United Nations Convention on the Rights of the Child (UNCRC) defines children as those aged 0–18 and young children as those aged 0–8

2 This paper is part of a wider Panos London initiative to generate public and policy debate and effective action to support children affected by HIV and AIDS. For more information, go to: www.panos.org.uk
Why involve children in responses to HIV and AIDS?

‘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.’

Saranya, aged 12
from the Children’s Unit of Positive Women’s Network, India

Children’s involvement is vital in HIV initiatives, in a range of social institutions, and in the context of early relationships and the informal settings that generate a child’s sense of self and agency with and in relation to others. Children’s participation may challenge fundamental relationships of power between adults and children, and such power relations need to be negotiated if children’s greater involvement is to be realised.

One in seven people dying of HIV-related illness worldwide is a child under 15. In the context of HIV, children have distinct experiences and needs. They have particular treatment needs, and require appropriate and accessible information and services. Access to sex education is also an issue for many children.

The particular vulnerabilities of girls and young women drive new HIV infections; four to five times as many girls and young women as boys aged 15–19 are HIV positive in high-prevalence countries. Girls are more likely to face sexual abuse and exploitation than boys, who may be at greater threat of physical violence. Girls are also more likely to be drawn into caring for sick and dependent adults.

For effective HIV prevention, the different realities, constraints and needs facing girls and boys need to be understood and addressed. Girls and boys should be involved both separately and together, using a variety of approaches to encourage their involvement in deciding on priorities for intervention. Yet initiatives for the meaningful involvement of people living with and affected by HIV and AIDS, which it is recognised are vital both in terms of rights and programme effectiveness, rarely involve children and young people.

It is now widely recognised that support for children affected by AIDS should be directed to their families and communities, as these are the primary settings where children receive sustained care, often with little external support. However, it is also evident that children may face adverse circumstances, including neglect and abuse, in the very same settings.
Children themselves often play a key role in providing ‘family and community’ support. The specific experiences and realities of girls and boys need to be addressed and not hidden behind assumptions about harmony in the local community. Yet rarely do we hear children’s voices, or see research about their perspectives and experiences.

**Involving children and addressing their realities**

‘Most people – I am not saying all – but most people listen to adults differently, I think. I think [adults] like to show off in a way, and just to say, “Oh well, she is only a child – who cares? We can do what we like because we are bigger.”’

Attempts to find appropriate and effective ways of involving children in responses to HIV and AIDS can benefit from the important lessons learned from more general initiatives to involve children in development, which began in the 1970s as part of the growth in participatory communication. The ‘child-to-child’ approach – used in more than 80 countries by the 1990s – is built on cultural traditions of mutual help. It regards children as active citizens who can share in decision-making, share childcare responsibilities and be involved in promoting health and nutrition in their communities and households. Additional impetus for children’s participation came from the so-called participation articles of the 1989 United Nations Convention on the Rights of the Child (UNCRC) and the African Charter on the Rights and Welfare of the Child. Article 12 of the UNCRC states that children’s views should be given due weight and inform decisions that affect their lives. Children are not given full adult rights under the Convention but are expected to be heard and to take increasing responsibility for decisions as their competencies grow. Article 5 urges parents and carers to gradually hand over responsibility to their children according to their ‘age and maturity’.

9 P Pridmore and K Harrison in V Johnson et al (1998), pp121 and 127, see note 8
At the same time, ‘developmentalist’ assumptions about children following a standard, linear path of maturation towards the more complete capabilities of adults are increasingly being criticised. Advocates argue instead that children need to be seen as people in their own right, actively engaging with their environment, and with a distinct set of competencies that need to be accommodated. Children need to be listened to and adults need to take what children say seriously.

‘Childhood’ is often talked about as a time of innocence, play and dependence, which must be protected. The reality may be very different. Children in the majority world often have considerable household and community responsibilities, including caring for siblings or parents who are sick (something that HIV and AIDS has made more common). Children are also important contributors to family livelihoods and often do paid work. It is important to recognise the diverse realities of children’s experience and to involve them in deciding what they want to change about their lives and how they can best go about it.

Of course, in cases where children’s labour is exploited, or they face social stress and difficult living conditions, these need to be acknowledged and mitigated where possible. But any actions should take care to avoid doing more harm than good. The Bangladesh garment industry in the early 1990s provides a cautionary example, as it illustrates how campaigns based on moral outrage can backfire when they do not incorporate children’s own perspectives. In this case, girls under 14 who were involved in relatively undemanding physical work were dismissed by their employer, who feared an NGO-led boycott. As a result, many of the girls had to find work in the more risky conditions of the street economy, including sex work.

Children’s realities must be the starting point for any development initiative. Yet research into children’s experiences and perspectives is scarce and, often, research data is not disaggregated to allow conclusions to be drawn about children of different ages.

Different societies may also have quite different approaches to child-rearing linked to their social context, history and culture, as well as changing household and family patterns (explored in a forthcoming Panos paper). Contemporary commentators, for this reason, talk of ‘childhoods’ rather than childhood, recognising that people’s understanding of childhood and adulthood will vary. The same may be said for ‘adolescence’.

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12 G Lansdown (2005), p6, see note 11
14 One-third of children in the North are also involved in paid employment. See A James, C Jenks and A Prout (1998) Theorizing Childhood, Cambridge: Polity Press, p113
16 Even the European study ‘Childhood as a social phenomenon’ found a widespread lack of disaggregated data on children. See J Qvortrup in A James et al (1998), p127, as note 14
18 V Johnson et al (1998), p6, see note 8
The scope for children’s participation in responses to HIV and AIDS

‘Now… I have the ability and the confidence to determine what is right and wrong… Recently, when my family and my community tried to make me marry against my will, I tried to convince them that this marriage was wrong. When discussions with my family failed, I protested against my proposed marriage with the help of the Bhima Sangha [working children’s union].’

Children’s equitable involvement in responses to HIV and AIDS is important in a wide range of public and private spheres: in institutions such as schools and local government, in participatory research linked to development of community projects, services and policy, and in child-led associations, clubs and ‘parliaments’. Active engagement in their daily lives, in households and more informal settings and relationships is also important, as the above quote illustrates. General studies of children’s participation have shown that they can make a valuable contribution in all of these contexts, from designing services and conducting research in community settings, to taking considerable levels of responsibility for their own healthcare.20

In the context of responses to HIV and AIDS, children as young as six have been involved in consultations to develop social security policy with government officials in South Africa.21 Children’s school-help clubs in Swaziland have set up vegetable gardens to grow food for poorer and more vulnerable members of the school.22 At community level in Zambia, young care workers have promoted community discussions on HIV transmission risks and reducing stigma and discrimination.23 In Mozambique, orphan and vulnerable children (OVC) committees have successfully engaged adults with children’s needs and views – and led to their addressing a wider range of vulnerabilities than they had previously considered.24

19 G Lansdown (2005), p34, see note 11
20 G Lansdown (2005), pp24–25, see note 11
22 Save the Children (2007), see note 5
24 Save the Children (2007), see note 5
Children and the media

Some projects have sought to actively engage the media to support children’s initiatives as well as to promote more positive images of their social contribution. The News Agency for Children’s Rights, ANDI, monitors and responds to national media coverage and supports independent journalism on children’s social and economic rights in Brazil.25 Panos Caribbean’s pioneering work with child journalists in Haiti and Jamaica seeks to empower children to report on their own experiences.26

Soul Buddyz, the multimedia communication initiative of Soul City in South Africa, combined providing information on HIV and AIDS and sexuality through television and radio drama with mobilisation of young people’s clubs. This has achieved considerable impact in terms of improving knowledge around HIV and prevention.27 Children have also been involved in producing television programmes to showcase innovations and solutions they have developed to the challenges in their own communities.28

Work with children brings a range of ethical issues to the fore, including child protection, informed consent, the need to make information age-appropriate and accessible, and confidentiality.29 A full child protection policy – developed with children and understood by them and all adults involved – is vital for anyone working on child participation.30

Informed consent may need to be continually renegotiated with younger children as their understanding of what they are committing to may change, and they need to feel able to choose not to participate. There are many ways to do this. In discussions on corporal punishment with young children in Zambia and Swaziland, children were encouraged to practise saying, ‘No, I don’t want to talk about that’ beforehand, so they were able to avoid talking about certain things if they chose not to.31

It is also important to recognise that children’s participation may be detrimental if attention is not paid to the quality of the process and the wider context in which it takes place. Tokenistic participation can lead to disappointment and disillusionment. Participation may also take children away from household chores, caring, agricultural and other work, or school. Encouraging children to participate may also bring strong reactions from parents or carers if they are challenged by children as a result.32

Child- and youth-led organisations

‘How would I convince somebody to join an organisation which is made by children? I have lost both parents and I live with my grandmother. Of course, the VSI [Vijana Simama Imara] supports us – for example, to join secondary school. Or we construct houses together for members whose houses have collapsed. We have already constructed three houses for this reason. If we would be alone, we couldn’t do such things. We organise such work in our meetings, where we decide who we shall support and when we will do the work.’

Filimena Victor, girl, aged 14
Bumiro district. VSI member since 2006

26 See www.panoscaribbean.org
28 See ‘Buddyz on the move’, www.sabceducation.co.za
30 For an example of a child protection policy, go to: www.savethechildren.net/alliance/resources/child_protection.pdf
32 Save the Children (2007), see note 5
33 K Madoerin (2008) Mobilising children and youth into their own child- and youth-led organisations, Johannesburg: REPSSI (Psychosocial Wellbeing For All Children), pp9–10
Support and funding for organisations led by young people themselves can help them set their own agenda, and develop the negotiation and dialogue skills that are part of engagement in public life. Two striking examples are Vijana Simama Imara (VSI), ‘Youth standing firmly together’, and Rafiki Mdogo, ‘Little Friends’. These sister organisations were set up in Tanzania with the support of the NGO Humuliza. Made up of children and young people aged 13–20 and 6–12 respectively, these organisations have provided children with emotional support, given them the chance to develop important life skills, and given them the experience of being able to plan and achieve goals they have set together with other children.34 This work has enabled children to redefine themselves as contributors to their own wellbeing and to their communities.35

VSI was explicitly influenced by the notion of ‘protagonism’ developed with street children in India and Latin America, which recognises how children’s associations can help to develop skills for active civic engagement and social awareness.36 VSI had a positive effect on local adults’ perceptions, with recognition of children’s many important contributions, including reinforcing a sense of community.

**Children’s networks and peer culture**

In addition to formal initiatives, it is important to recognise children and young people’s involvement in their own peer networks and their motivations for participation. Some adults see such interaction as problematic, given that it may operate outside of the immediate influence of parents or adults, and therefore challenge their authority.37 Their concerns are mirrored in popular media images that tend to present children either as passive or as a threat to their community.38 The negative view taken in the media of assertive children who ‘know their rights’ is a more recent phenomenon also common in everyday discourse and with widespread international currency, something we return to below.

Boys’ peer group culture provides another challenge. Research by David Plummer in Jamaica illustrates a pattern with much wider reach – where risk-taking and multiple sexual partners are seen as integral to the kind of masculinity that is valued by boys and youth.39 The relative insulation of such peer culture from adult and parental influence, and the role of older boys in passing this peer culture onto younger ones present important challenges to HIV prevention efforts.

Peer culture, however, is also influenced by global media and consumer trends, the gender norms of wider society, and changing relationships between the generations.40 Addressing harmful gender norms among children – a key to successful HIV prevention – demands, just as with adults, participatory education and life skills that allow people to reflect on their own relationships and actions. But it also requires initiatives that address the wider institutional, economic and legal factors that underpin gender norms in society more broadly41 – what is increasingly being called ‘structural prevention’.42 Again, it is vital to focus on children’s realities, and to engage them in designing initiatives to tackle complex social issues like gender inequity.

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34 See note 33
36 K Madoerin (2008), p3, see note 33
37 A James et al (1998), see note 14
38 S McNeill in V Johnson et al (1998), p32, see note 8
40 A James et al (1998), p73, see note 14
41 Panos (2006), see note 6
Many carers struggle to find a balance between care and discipline in bringing up children.

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Children who ‘know their rights’

‘Our children didn’t come late home, or argue with us. It started with these younger ones [the grandchildren]. They tell us they have rights. We will go to prison if we hit them.’

While there is a range of distinct settings where children’s participation may be addressed more systematically, in everyday contexts many of the issues around children’s participation are less clear-cut. Anthony Swift describes how the tensions and ambiguities around children’s rights in South Africa play out on the ground in vivid detail. Carers attempt to bring up children with a mixture of care and discipline in neighbourhoods they perceive as dangerous, in the context of shifting parental authority and changing power balances linked to child benefits, education, children’s rights, and the growth of consumerism. At the same time, children may face high levels of violence and abuse in their homes and communities which need to be addressed urgently.

Situations in which adults’ rights are routinely compromised make addressing children’s rights even more difficult. It is therefore important to address the social and economic realities of poverty for adults as well as children, if meaningful rights for children are to be realised.

People’s understanding of participation varies depending on the context, and it is important to work with communities and families to convince them of the value of children’s involvement as well as addressing any harmful attitudes and practices. In South Africa, for example, many carers agree with the spirit of laws to protect children but feel belittled and undermined by the fact that they have been introduced with little local consultation; they can also feel undermined by the fact that children appear to know more about their rights than adults do.

The fear of children asserting their rights and fuelling family conflict is contradicted by the experience of the two child-led organisations in Tanzania, VSI and Rafiki Mdogo.

43 A Swift and S Maher (2008), p50, see note 35
44 A Swift and S Maher (2008), pp48–52, see note 35
46 Vicky Sikhakhana of TREE (Training & Resources in Early Education) in Durban, South Africa, personal communication
47 Richard Mabala of Tamasha, in Tanzania, reports a similar experience with children’s out-of-school clubs: initial suspicions from parents gave way to recognition of the skills and knowledge contributed to the community, personal communication
48 G Lansdown (2005), p17, see note 11
Assessing children’s participation

‘I wouldn’t have believed a child of two and a half could have been able to understand what was being asked of her so easily.’

The growing interest in children’s participation has seen an increase in the number of projects and initiatives that seek to involve children in work on HIV and sexual and reproductive health. The concept of participation, however, has been used inconsistently to describe children’s involvement at a range of levels.

Degrees and quality of children’s participation

The ‘ladder of participation’ adapted by Hart outlines a variety of different levels of participation, ranging from ‘manipulation and tokenism’ to ‘child-initiated’ and ‘shared decision-making with adults’.50 Lansdown’s model sees involvement stretching from consultation, through participatory processes, to a self-initiated process. In consultation, children’s views are taken into account in an adult-initiated process; in participatory processes, children are actively involved in the development, implementation and evaluation of projects; in a self-initiated process, children themselves are empowered to take action and are not merely responding to an adult-defined agenda.51

Abrioux developed a less absolute framework – a spherical model of participation – to allow recognition of small steps that may be made to improve children’s lives in difficult social and political contexts. In Kabul, for example, girls face restrictions on education and access to public space. Here, any steps towards discussion and participation – even coming out to the meeting centre where activities are held – represent a significant advance.52

A review of recent research and unpublished reports on children’s participation in HIV and related initiatives (125 documents published from 2003–2007) found an increasing interest in children’s participation, but only six rigorous project evaluations.53 Young people in a variety of roles had contributed considerably to the overall impact of projects, when given appropriate support. However, none of the studies looked at the participation of children younger than nine. Other research gaps include: review of evidence on girls’ and boys’ participation; the impact of children’s involvement on communities; and the impact of their involvement on distinct HIV programming areas.

49 G Lansdown (2005), p33, see note 11
51 G Lansdown (2005), p15, see note 11
52 V Johnson et al (1998), p60, see note 8
With regard to evaluation, the research review suggests some common ‘domains’ where the impact of children’s participation could be more systematically evaluated: on organisational structure and process; on the community or environment; on individual young people; and on programme effectiveness. Indicators should capture the extent and quality of young people’s participation throughout a programme’s life cycle, the types of responsibility they take on, the number of young people involved, their demographic characteristics and how well they represent the target group. Indicators should also gauge the level of continuity of the process – for instance, is participation institutionalised and mainstreamed, or a one-off event?

Project evaluations should also consider changes in power relations both between adults and children, as well as among children themselves, where differences of gender, ethnicity, class and disability are important.
Children’s communication styles

‘This is a flower. It is shining with the branches. A person is taking care of this flower. If this flower grows up there will grow some other young flowers out of this one... I have friends, [we] sing together, I really like singing. I’m 11 years old now.’

Children do not necessarily express themselves in ways that easily fit into conventional adult processes for decision-making. The different competencies and communication styles of children of different ages demand a range of creative media and approaches. Such approaches are informed by traditions of participatory communication, which recognise that children, like other less powerful groups, may be ‘unable to express their reality in ways that are acceptable to the dominant groups that control both means and modes of expression’.55

Children need to be able to express themselves in ways that they feel comfortable with and in their own terms.56 This will be different for more analytical teenagers than for younger children, with some practitioners suggesting that children work best in groups where the age difference is five years at most.57 Building the necessary relationships of respect, trust and openness takes time. Activities need to be grounded in children’s everyday experiences. In practice, this means making activities engaging and age-appropriate, and using a variety of media – like drawing, painting, music, dance, photography, storytelling, drama and role-play, and games.58

It may also be important to find appropriate ways to involve children and young people as equal participants with adults in community planning and priority-setting exercises, rather than running separate activities aimed at their involvement.59 Pictures and visual representations of shared decisions and outputs can be useful tools as they help to reduce the degree of adult interpretation that may be found in written reports. Participatory video also has a more direct quality,60 and can be used to present children and young people’s opinions in a way that is less open to interpretation and mediation.61 Verbal presentation should not be exclusively relied upon, but children should be encouraged to use physical expression to communicate, for example by using drama, something that is particularly important for young children.

A range of child-centred communication approaches to HIV and AIDS have sought to work with, listen to and involve children, including younger children, although their needs are less often addressed.62 ‘Memory books’ (with photos, personal messages and information about relatives and carers) can be a particularly useful tool for promoting discussion between children and adults on all aspects of HIV and AIDS, including preparing for the death of a parent.63
Young children’s communication

Young children (those aged 0–8) are less able to analyse situations and are likely to express themselves differently from older children. Glynis Clacherty describes a range of approaches that she and colleagues have used in different settings to involve young children including giving input into social security policy in South Africa, gathering children’s experiences of HIV and AIDS, and discussing corporal punishment in Swaziland and South Africa.

Giving children space to share

In consultations with children aged six to examine the impact of social security legislation on poverty in South Africa, researchers asked children to draw what they had eaten for breakfast. When the children all drew pictures of a commonly advertised cereal, the facilitator encouraged them to continue to talk about their breakfast, and then once again asked one child (who she knew to be quite forthcoming) what she had had for breakfast. This child replied that she had just had tea for breakfast, and then another said they had only had water. Another round of responses revealed that quite a few of the children had not eaten breakfast at all. The facilitator had accepted what the children said, but without contradicting or correcting them, created the space for them to open up about their real experiences.

When talking about difficult experiences, dolls or puppets, as well as drawings of hypothetical figures, have helped young children to communicate by allowing them to use the dolls to talk about their experience in the third person. Ubulele, a psychosocial support organisation in South Africa, has also found that using ‘persona dolls’ has helped young children to engage in discussion and explore solutions to the problems they face.
Children facing the future

While children’s lives are negatively affected by HIV, they are also closely involved in the responses of their households and communities to the epidemic. Children are becoming protagonists for change, and have shown that they can take on new responsibilities and tackle creatively many of the challenges of poverty and HIV and AIDS. Their efforts and energy deserve the support of the development community and its resources.

Yet despite growing awareness of children’s rights and the need for their participation – which is clearly evident in the number of projects that aim to involve children – many countries still struggle to realise children’s meaningful participation in practice. Participatory approaches – with children, just as with adults – demand time and resources if they are to be effective and really empower children to be involved in, and shape, HIV and AIDS programmes. This requires longer-term, more flexible programming that takes the necessary time to build relationships of trust and to find effective ways of working with and involving children of different ages and backgrounds.

This is not business as usual. Without such a change in emphasis, children’s participation is likely to be tokenistic and manipulative, and risk their early disillusionment with the possibilities of democratic engagement and change. There is potential however, to build on the documented successes of involving children in the decisions that affect their lives, to give them the tools and space to participate effectively in responses to HIV and AIDS.
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Inclusive
We believe that embracing the views of poor and marginalised people is essential for sustainable and effective development.
Taking part in dialogue and debate contributes to a healthy and vibrant society.

Empowering
We believe that poor and marginalised people should drive and shape the changes needed to improve their lives.
We enable people to share information and ideas, speak out and be heard.

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We believe people need accessible information reflecting a wide range of views.
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We shed light on ignored, misrepresented or misunderstood development issues.
We believe that the views of poor and marginalised people give greater insight into their lives and offer unique perspectives on the challenges they face.

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PHOTOS: PANOS PICTURES
This paper explores the growing interest in involving children – including young children – in responses to HIV and AIDS. The paper looks at a range of barriers to children’s participation, the challenges of accommodating the distinctive communication styles of children, and highlights promising initiatives to support children’s communication and participation.

*Seen and heard* challenges policymakers and practitioners to build on the documented success of involving children in decisions that affect their lives, to give them the tools and space to participate effectively in responses to HIV and AIDS. It emphasises the importance of listening to the voices and experiences of children, and recognising their energy and creativity in addressing the lived realities of HIV and AIDS in their households and communities.

Cover Image
The children of the extended Mbele family play on an abandoned minivan in the family compound. Children have a key role to play in supporting families and communities affected by HIV and AIDS and their voices need to be heard.

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