Child and Older Carer Participation in Events Are We Really Learning?

By the Regional Inter Agency Task Team on children and AIDS in East and Southern Africa Conference child participation task team

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Note that key reports and documents mentioned in this paper can be found on the AIDS Portal under the section on the RIATT www.AIDSPortal.org
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Glossary of terms and concepts

ART  Antiretroviral Treatment
ARV  Antiretroviral
AIDS Acquired Immune Deficiency Syndrome
AU  African Union
CP  Child Participation
CSOs Civil Society Organisations
FAO Food and Agriculture Organisation of the United Nations
FGDs Focus Group Discussions
GPF Global Partners Forum
HAI Help Age International
HIV Human Immunodeficiency Virus
IAC International AIDS Conference
IATT Inter Agency Task Team
ICASA International Conference on AIDS and STIs in Africa
M&E Monitoring and Evaluation
MCDGC Ministry of Community Development, Gender and Children in Tanzania
OVC Orphans and Vulnerable Children
PASADA People with AIDS in Dar es Salaam Archdiocese
RIATT The regional inter agency task team on children and AIDS in East and Southern Africa
RIATT CPTT The regional Inter agency task team on children and AIDS in East and Southern Africa Child Participation Task Team
SADC Southern African Development Community
SC Save the Children
STIs Sexually Transmitted Infections
UN United Nations
UNAIDS The Joint United Nations Programme on HIV/AIDS
UNCRC UN Convention on the Rights of the Child
UNDP United Nations Development Programme
UNICEF The United Nations Children Fund
Yomnet Young People’s Media Network
1. **Background**

The East and Southern Africa Regional Inter Agency Task Team (RIATT) on Children and AIDS was formed in October 2006 to achieve the February 2006 Global Partners Forum’s (GPF) recommendation of establishing regional task teams that carry out global and regional objectives relating to children in the context of HIV and AIDS. The RIATT comprises the AU, SADC, SADC Parliamentary Forum, international cooperating partners, civil society organizations, academia, and UN organizations, including UNICEF, UNAIDS, UNDP and FAO. The RIATT’s key purpose is to serve as a multi-sectoral partnership to build consensus around a regional strategy and response for children affected by HIV and AIDS.

As a step towards building a regional strategy on children and AIDS, the RIATT prioritized holding a regional conference as a follow up to the previous East and Southern Africa meetings on children affected by HIV and AIDS in Lusaka (2000) and Windhoek (2002). The conference in Dar es Salaam from 29 September - 2 October 2008 aimed to provide a platform for broad interagency and intergenerational interactions relating to key evidence based findings and recommendations on universal access for children. It sought to identify, share and motivate for the implementation of evidence based, cost-effective and at-scale interventions for use at national levels for children affected by HIV and AIDS. Approximately 300 delegates from 19 East and Southern African countries, including 23 children (7.6%)\(^1\) and 12 older carers (4%), convened for the “Getting it Right for Children” Conference. Delegates included senior level government representatives, UN agencies, civil society organizations, international cooperating partners, and academia.

Child participation and older carer consultations took place independently in eight countries and recommendations emerging from these meetings were brought to the conference. The conference was designed to ensure maximum participation of all adult and child delegates with evidence-based findings and recommendations discussed each day by country delegations in a peer learning and review process. The morning sessions of the conference provided a platform to present, share, and discuss evidence-based findings and recommendations from research and programme experiences at regional and national level. Afternoon sessions, including a “marketplace meeting” and “gallery walk” enabled participants to interact with each other and identify key lessons learnt in the region, allowing country level priority actions to be drafted. These action plans were taken back to the countries and shared with the broader orphans and vulnerable children (OVC) networks and/or mechanisms\(^2\). Importantly, the conference’s outputs, which fully incorporated the children and older carer’s recommendations, have formed the basis for the RIATT 2009-2011 strategic framework and work plan.

An evaluation of the child participation process was carried out using structured interviews with the 23 child delegates and key members of the child participation task team. A post-conference evaluation of the conference child participation process was conducted with the 250 delegates using a survey questionnaire by participants. The interview questions were

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1. In the recent World Congress III in 2008 10% (c300) delegates were children and adolescents
2. See Conference Report, RIATT (found on the AIDS Portal www.AIDSPortal.org)
based on the five guiding principles of child participation from the Asian IATT child participation working group guidelines\(^3\). Using the results from this evaluation, this paper explores the concept of child participation in conferences and events, while reflecting on the older carer consultation process that took place in tandem. We hope that the report will serve as a resource for future similar initiatives engaging with children.

2. **Child and Older Carer Participation in Events: Are we really learning?**

This paper will explore the concept of child participation in conferences and events reflecting on the recent child participation process which led to the Regional East and Southern Africa Inter agency Task team on Children and AIDS (RIATT) conference that took place from 27\(^{th}\) September to 2\(^{nd}\) October 2008 in Dar es Salaam, Tanzania, “Getting it Right for Children” Moving towards universal access, prevention, care and treatment for children affected by HIV and AIDS. It will also reflect on the older carer consultation process that took place alongside the child consultation process.

Participation is considered a human rights based approach to development as expressed in development theories such as those by A. Sen and P. Freiro. Participation is a process and the results depend on what extent it is truly effective and meaningful as referred to in the Hart’s “Ladder of Participation,” see fig. 1. Adults are the duty bearers for children and therefore they have responsibilities for which they must account to children. In addition, children as rights holders also have a right to participation in for example, decision making, consultations and programme implementation.

Through participating, the rights holders increase their stake in for example the programme or decision making process, hence it is the process of participation that is as important as the outcome.

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\(^3\) The Minimum Standards for Consulting with Children was developed by the Inter-Agency Working Group on Children’s Participation as part of the process to ensure meaningful participation and high-quality children’s participation in the UN Study on Violence against Children in East Asia and the Pacific Regional Consultations and associated meetings.

Child Participation is a fundamental human right for all children as well as a guiding principle of the UN Convention on the Rights of the Child (UNCRC). Several articles of the Convention relate to children’s participation (Articles 12, 13, 14, 15, 17 and 23) although article 12 is more explicit, outlining that the child has a human right to “express (his or her) own views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.”

3. Child participation in conferences

RIATT conference organisers decided from the beginning when deliberating the regional conference, that child participation is key for ensuring that national HIV and AIDS policies respond to children’s needs. The regional inter-agency child participation task team (RIATT CPTT), made up of representatives from UNICEF ESARO, REPSSI and Save the Children Sweden (on behalf of SC Alliance), was established as part of the RIATT conference steering committee to develop the child participation process leading up to the RIATT conference. The RIATT CPTT based their approach on the Inter-Agency Working Group on Children’s Participation in Asia guidelines. The guidelines are based on five principles of participation:

1. Transparency, honesty and accountability
2. A children – friendly environment
3. Equality of opportunity
4. Safety and protection of children
5. Commitment and competency of adults

The issue of child participation in consultations related to humanitarian and development work is a complex and contested one. There exist clear guidelines for child participation and many lessons have been learned about how it can take place. However because of the intensity of the cultural, social and economic dynamics surrounding child-adult interactions, there are ongoing challenges and issues about the different ways in which children can participate in different processes and events.

The active resistance, lack of understanding or enthusiasm for participation of children, adolescents and young people is probably a reflection of the fact that:

1. There is often very little ethical and meaningful perception outside the events and conferences. Rajani argues that the first priority is to develop structured, institutional participation with clear lines of representation and inclusion on a day to day basis within the institutions of society, such as schools, communities and local governments. Unless this

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6. UN Convention on the Rights of the Child
8. These include Minimum Standards for Consulting with Children, Asian Inter Agency Working Group on Children’s Participation 2007, Practice Standards in Children’s Participation, International Save the Children Alliance 2005
happens, ‘event participation’ or trying to develop strong and ethical participation in national and international conferences is like trying to place a beautiful (and probably very heavy) roof on rickety walls that cannot take the strain.

2. The extent and nature of children’s participation will reflect the extent and nature of participation in society as a whole. On the whole, adults do not accept the validity and potential of such child/adult partnerships. It is not very realistic to expect substantive participation of children in their societies when their parents are unable to participate. If the immediate duty bearers of the children do not also have their rights fulfilled, they are not likely to prioritise those rights for their children.

What was clear from the review of the different experiences of children participating in conferences, was that despite good intentions, well researched guidelines and the establishment of agreed upon minimum standards, the nature of conference organising means that these minimum standards have to date never been met in their entirety. This begs the question as to whether organisations should therefore forego participation on the grounds that minimum standards have been violated or try to negotiate as ethical and meaningful a participation as possible within the constraints laid down? Mabala contends that:

“We ‘do’ participation because it is a good thing to ‘do’ and believe that in doing so, the positive aspects will float to the top but that is not necessarily the case and in a world where many are quite sceptical of such participation, if it is not carefully prepared and implemented it can do more harm than good, to the child participants themselves, to the causes that they espouse and to the cause of child participation as a whole”.  

Furthermore, as Landsdown points out in her work on the evolving capacities of the child, standards of protection differ from one country to another, and children, especially adolescent children, do not always take kindly to over protection which can retard the evolving capacities of the child.

This then is the dilemma facing participation of children and adolescents in conferences. On the one hand, advocates of child participation want to ensure a perfect enabling environment for child participation, but on the other hand they need to interact with an imperfect world which is not always appreciative of such stringent standards. That is why the Minimum Standards prepared by the Inter Agency Working Group on Child Participation in Asia are both a powerful statement in favor of what needs to be done and a challenge in their uncompromising comprehensiveness which might not always be possible. However, they do provide a measure and a checklist against which the organisers of any participatory event can measure themselves.

The above difficulties are real and the potential for wastage and harm are significant. That said, time and again experience shows and documentation indicates that when children participate appropriately and meaningfully, the breadth and depth of their observations shows clearly how important it is to consult children. They see and understand far more than adults.

would maybe like them to, particularly in issues relating to the way they are treated or mistreated. In the RIATT consultations they were appreciative of those services and support given to them but showed clearly where the systems were not succeeding, in terms of provision of educational support, health care and above all guardianship.

4. **The case of the child participation process in the RIATT conference**

Operating from the premise that ethical and meaningful child participation is necessary and in fact possible, the RIATT CPTT surveyed the challenges and lessons learnt from different types of child participation in conferences, and identified three main types (see fig. 2):

The RIATT CPTT recommended the second option as the most viable within the context, taking into account the fact that the adults had already begun consulting and organising around the conference and had not included children from the initial planning stages; the complex regional nature of the consultations, the lack of a regional children’s organisation and in some countries the lack of national children’s organisations and networks to work with.

The conference organizers proceeded to put into place measures to ensure that child participation remained integral to the overall vision of the conference, and that the conference was not an isolated event but part of a longer process of child participation that would tap into and strengthen existing processes.

In this light a consultation process took place in eight countries (Burundi, Ethiopia, Kenya, Lesotho, Malawi, Mozambique, South Africa and Tanzania) with around 4000 children. Of these children, 23 participated in the RIATT conference to represent their peers, where they shared the key messages on children and HIV from the consultation processes held in their respective countries.

There were three overall aims of the child participation process:

1) To engage directly with children’s networks to strengthen their participation at national and regional level in influencing policies concerning care and support for children affected by HIV and AIDS. It was hoped that this would then create a platform to ensure that children have the opportunity to discuss pertinent issues among themselves and then put forward their views and issues as an integral part of the main conference.

2) To promote child-adult partnerships which focus on enhancing children’s ability to participate in national processes and the adults ability to engage with children in their planning.

3) To promote a conference organized jointly with adults and children participating in the consultation process to share thinking and ideas for future action. Children would be involved as speakers, leaders and delegates in an ethical and meaningful manner.
The RIATT CPTT advocated for, designed and coordinated the regional children’s consultation process supervising the work of the consultant institution, Tamasha, who contributed to the design and managed the process. Support was given at a country level by the RIATT CPTT where it was required. The RIATT CPTT also designed and coordinated the media production process that was set up as an integral part of the consultation process and recruited a media organization, Jungleworks, who had experience at working with children and adolescents to carry out this process. The preparation phase for the overall child participation process was extensive and it was necessary for intense advocacy at the regional level to ensure the process was integrated into the overall conference process and not viewed separately and that there was sufficient time and funds for the process to take place.

**Fig. 2**

<table>
<thead>
<tr>
<th>1. Planning adult conferences with children invited to participate.</th>
<th>2. Planning conferences organised jointly for adults and children to share thinking and ideas for future action on a given issue.</th>
<th>3. Conferences organised with and for children, with adults as facilitators.</th>
</tr>
</thead>
</table>
| **Examples** | • UN General Assembly Special Session on Children, New York, 2001  
• CRC 10th Anniversary Commemorative Meeting, Geneva, 1999  
• Winnipeg International Conference on War Affected Children, 2000  
• IAC 2006, 2008  
• ICASA 2006, 2008  
• GPF 2008 | • Understanding with Children: coping with floods in Bangladesh, 1996  
• Young People’s Voices on HIV/AIDS, New Delhi, 1998 (this can be at the national level)  
• World Congress III 2008 | • Millenium Young People’s Congress, Hawaii, 1999  
• Commonwealth Children’s Summit, Durban, 1999  
• Forum with Working Children, Oslo, 1997  
• Children’s Citizenship & Environment Conf, Karakalpakstan 1999 |

**The role of children and adults**

**Children** not involved in the design or organization of the conference. Participating as speakers and delegates, and might be asked to:
- Tell “life” stories
- Describe the work of their organization
- Comment on children’s experiences in the relevant field
- Outline their demands for change

**Adults** have total responsibility for the event at all stages. In particular, they should take responsibility for ensuring that in an event designed both by and for adults, efforts are made to ensure that the children are adequately supported, made to feel welcome and treated with respect by the adult participants.

**Children** involved both as speakers, workshop leaders and delegates. They may also be involved in the planning process.

**Adults** involved at all stages of the event - the extent to which they share or delegate power over decision-making with the children must be negotiated at an early stage.

**Children** involved at the earliest stages of planning through to the event itself and the production of any conference report. Indeed, the initiative for the event might well come from children themselves. They could be involved in:
- Defining aims and objectives;
- Determining the structure of the event;
- Planning the specific contributions;
- Inviting speakers;
- Chairing and presenting;
- Running workshops;
- Evaluation;
- Conference report.

**Adults’ role** to offer the skills and knowledge which the children identify as necessary to support them, including:
- Provide information where needed
- Provide support in tackling problems and difficulties as they arise
- Advise on child protection or safety issues, particularly if the conference is residential
- Advise on venues, administrative and organizational matters
- Help with funding and management of the finances
- Help with media coverage, press releases
- Help with dissemination of conference outcomes
5. How did children participate in the RIATT Conference?

The intention of involving children in the RIATT conference was to learn from their insights and also from the solutions that they had to offer regarding the response to HIV and AIDS mitigation for children and adolescents. In this way, the children were given the space to consult with their peers in the eight participating countries before the conference and to come and represent their country at the conference. Children and adolescents were trained in media skills and supported to develop films which were presented at the RIATT conference and further represented the children’s voices from their countries. The children were also taken through the possibilities that exist in the context of new media and produced a blog which was set up. You can visit the children’s blog and leave a message at [http://listentoourvoice.blogspot.com](http://listentoourvoice.blogspot.com).

National meetings took place in each of the eight countries where children and adolescents had the opportunity to share their findings and to democratically select their representatives to take part in the RIATT conference. The children and adolescents selected from the national consultations took part in a children’s special session. This was a meeting that took place on 27th and 28th September in Dar es Salaam. The purpose of the meeting was to prepare children and adolescents for their effective participation in the RIATT conference. They could choose their representatives to speak during the RIATT conference, they could collectively decide on their recommendations and call for action. This led to a more meaningful participation of children and adolescents throughout the RIATT conference.

The diversity of the children from the different African countries brought new and different ideas, voices and approaches, with common themes and challenges which were heard throughout the RIATT conference. This added value in various key moments of the RIATT conference as explained below.

6. Successes

Modalities of child participation: national representation, in-country consultations before conference, large numbers of children consulted, child-led peer research

The modalities of child participation in the conference were significantly different from previous conferences which also involved children as referenced in the above section on child participation in conferences. For example, agencies at national level worked together to try and ensure a more national representation rather than that based on the networks of each individual agency and space was made for the children to consult with their fellow children so that they were able to speak on their behalf at the regional conference.

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12. There is a DVD available from REPSSI of the films that the children produced including a short documentary of the child participation process.

The Tamasha guidelines\textsuperscript{13} set the standard in relation to how the consultation process was to be carried out. A national level task team was established to oversee the consultation process in each country made up of key organizations working with children. Children were identified by agencies working with children’s groups and networks to lead the consultation process. These children met to plan how the research would take place and to look at the key issues to be addressed.

A total of 500 to 1,500 children in each country were consulted by their peers (fig. 3). The focus was on asking children (particularly vulnerable and those affected by HIV and AIDS) what they thought was being done with regard to children affected by HIV and AIDS in their country, to find out to what extent children had benefited from programmes of government and other actors and what more needed to be done. The girls and boys who participated were between the ages of 13 – 18 years. The length of time for the peer led community consultations varied between 7 days and 1 month.

After carrying out the research the child and adolescent researchers met together at a national level to discuss their findings and agree on the key issues that the child delegates would take through to the RIATT conference. Participatory and child friendly methodologies were used in order to discuss and decipher the priority issues at a national level. In some countries there were meetings between the adult delegates including older carers prior to the RIATT conference. Unfortunately, the structure of the consultations and research carried out varied as in some countries the Tamasha participation guidelines were not completely followed as explained later.

In Tanzania care was taken to select children from different backgrounds to be involved in the child led consultation process as shown in the example in fig. 4. This was reflected in the wealth of discussions that took place during the national level of consultations in Tanzania. The in-country consultations provided space for children to discuss and prioritise their issues for representation at the conference.

<table>
<thead>
<tr>
<th>Country</th>
<th>Number of Children</th>
</tr>
</thead>
<tbody>
<tr>
<td>Burundi</td>
<td>406</td>
</tr>
<tr>
<td>Ethiopia</td>
<td>200</td>
</tr>
<tr>
<td>Kenya</td>
<td>240</td>
</tr>
<tr>
<td>Lesotho</td>
<td>450</td>
</tr>
<tr>
<td>Malawi</td>
<td>208</td>
</tr>
<tr>
<td>Mozambique</td>
<td>480</td>
</tr>
<tr>
<td>South Africa</td>
<td>350</td>
</tr>
<tr>
<td>Tanzania</td>
<td>1500</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>3834</strong></td>
</tr>
</tbody>
</table>

**Selection in Tanzania**
- Compassion (World Vision)
- Child headed households
- Children living in foster care/families from urban and rural areas
- PASADA (REPPSI)
- Children living with HIV/AIDS from urban areas
- Humuliza (REPPSI)
- Children affected by HIV/AIDS from rural areas
- Dogodogo Centre (Plan)
- Children making live in the streets from urban areas
- Junior Council of Tanzania (MCDGC and UNICEF)
- Active children in child-led initiative and those with interest in the process from urban and rural areas
- Living Water (World Vision)
- Neglected children because of their disabilities from urban areas
- YOMNET (UNICEF)
- Children in media from urban and rural areas
- TAMASHA (self)
- Children from deprived urban areas
In countries where child-led peer research took place, it made a strong impact on the children involved as noted in the following excerpts from Tanzania and Burundi.

In Burundi, one of the child delegates explains, “I had the chance to discuss with other children from up country ... especially those being looked after by aged relatives. I found out how much children placed in families suffer. Some families consider them to be a burden, other families think, wrongly, that since these children are living with HIV, they are going to die at any time so it is useless to waste money on them,” (Girl, aged 17, Burundi)

“In Tanzania, the vice chair of the Junior Council of Tanzania said she was really shocked when she went into the villages because she found that all the services she took for granted were not available there. Not only did it mean that she made a substantive input into the children’s consultation but it also strengthened her resolve as Vice Chair of the Junior Council to ensure that all children attain their rights.”

These examples show the importance of meaningful child participation where children are given the space to learn from each others’ experiences and see the critical role they can play in identifying the different challenges that their peers are facing.

The consultations and research also improved the confidence and determination of the child researchers:

“I can also say that all the children who participated in the consultations are more self confident. They have learned that they are not alone in their suffering and that somewhere there is someone who is suffering more than them. They have learned that a child affected by AIDS is a child just like any other” (Boy, aged 13, Burundi)

The children took their role as researchers very seriously and as a result learned a lot from the process (see Fig. 5). The consultations reached out to a large number of children which varied between countries. In Tanzania, 1,500 children had a chance to input their views whereas in Mozambique around 500 children did. In addition, the consultation process added new impetus to the efforts to create more structural and sustainable networks of children.

Selection of children for the regional conference: peer-led selection, increased levels of preparedness

Selection of the child delegates for the conference was carried out in a participatory way allowing the children to vote for who they wanted to represent them. It was a very

15. Ibid
exciting process for the children. 90% of the selected child delegates said in the evaluation that they had been chosen in a fair way. 75% claimed there was no discrimination in the selection of the child delegates while 25% said there was some discrimination. In Burundi, “the children chose a wide variety of representatives, ranging from age 13 – 17 and including children living with HIV, orphans, children living on the street as well as journalists and parliamentarians. This method of selection also prevented any lobbying by agencies for “their” children.” 17

The children came to the conference prepared to share with their peers and the other conference participants. From the evaluation18 almost all of the children said they had a good idea of what they were going to be expected to do before they came to the children’s special session and main conference indicating their level of preparedness.

Participation at the conference: children’s special session, simultaneous translations, chaperones, appropriate venues

The children had a productive and stimulating two days in the children’s special session, facilitated by Tamasha where they could share their experiences and findings from the consultations with each other and prepare for the main conference. From the conference evaluation it appears that all of the child-delegates interviewed were happy with the discussions around the recommendations from this session. The special session took place at a smaller hotel then that of the main conference and was arranged in an informal manner creating a safe and empowering environment for the children to discuss their findings from the in-country research and prepare what was going to be presented in the main conference. The children were encouraged to share their opinions and experiences openly. Evening cultural events were also organized by the children which created a sense of working together as a team. The older carers were also invited to one of these events.

Overall including the children’s special session and the main conference, almost all of the child delegates were happy with the translation process and facilities. The children also reported that the meeting rooms, accommodation and food were suitable for children of their age19. Some of the adult delegates comments from the evaluation in relation to whether there was a child friendly environment include, “there was good organization to ensure freedom of expression, there were interpreters/facilitators of the main UN languages including Swahili, the chaperones were given the responsibility of communicating with the children in their mother-tongue.”20

At the RIATT conference itself, children and adolescents made powerful presentations on behalf of all child delegates and children with whom they had consulted for example at the opening and closing. They reflected on the research they had carried out in their respective countries and the discussions they were able to have during the children’s special session. They supported the sensitization session on how to listen to children, also carrying out a role play for the adult delegates to understand further the importance of this. They took part in their respective country team discussions following the plenary sessions where they could share their opinions on the presentations made and the findings from the research they

17. Mabala, R. RIATT Conference Children’s Participation Tamasha Report
19. Ibid.
20. Ibid
had carried out. They carried out interviews with the media and some key adult delegates who were present. Children and adolescents had their own “space,” a hotel room set aside for the children to meet in where they could rest, prepare presentations and discuss their feelings and reactions to their experiences in the RIATT conference. They also received prominent guests in their “space” where they were able to discuss in a more intimate way with these adult delegates.

Each country team gave comments on the final RIATT recommendations and children and adolescents had the opportunity to ensure their recommendations were included in the country team discussions. The level of understanding by the children, of the recommendations coming out of the conference, is emphasized in the evaluation where 74% of children said they clearly understood the recommendations from the conference. The presentations from the children made a significant impact on the adult delegates as shown in the conference evaluation. Delegates recognized the “power and the authenticity of the children’s voices, particularly as they were speaking on behalf of a body of peer to peer research carried out by them and their fellow children in their countries.”21 An overwhelming majority of the conference participants (98%) were of the opinion that child delegates were given ample opportunity to make presentations during the conference. Some of the further comments from participants in support of this include that child delegates should have been given more opportunities to make presentations at the plenary and there is need for children to be fully integrated as part of the conference proceedings.22 This may reflect that the children were not involved in designing the conference and may not have been engaged fully in all presentations if the presentations were not carried out in a child friendly manner.

6.1 The children and adolescent recommendations and key issues

The child delegates’ presentations and interactions at the conference influenced the overall recommendations from the conference directly impacting how the RIATT recommendations were structured or reinforcing the importance of certain issues. For example, while the children recognized the importance of the emphasis on family and community there is also a need to recognize that both are not always acting in the best interests of the child and that the issue of deep rooted stigma and child abuse in the family and community need to be addressed if children’s rights are to be fulfilled (see annex I points 1 and 2). This influenced RIATT recommendations 3, point 4 and recommendation 4, point 2 (see annex 2) and were a caution to the increasing focus on the community and family by the adult delegates.

Birth registration is another example (annex I point 3), Ms. Nhlapo, a child delegate from South Africa, highlights the issue of the cost of birth registration emphasizing the challenges of accessing the children’s entitlement to birth registration in order for children to access health and education services. This point reemphasized the importance of RIATT recommendation 3, point 8 (see annex 2).

The importance of effective and meaningful child participation was reiterated by the children, showing the real difference that can be made if children are involved (annex I, point 4). As Ms. Nhlapo stated, “children know what is happening and if you listen to us… you will get lots of information about what is happening on the ground. You will also get a lot of new ideas that will help us all to get it right.” The participation of the children in the conference and the interactions that they were able to have with the adult conference delegates influenced RIATT recommendation 2, point 4 (see annex 2).

The importance of education, was emphasized and was clearly a priority for the children. Ms. Nhlapo highlighted (annex I, point 5) that secondary education is not accessible to all and is not free and this was included in the RIATT recommendation 4, point 3 (see annex 2). There was also a strong recognition that life skills education in schools was not sufficient and could be improved upon as Ms. Nhlapo mentions (annex I, point 6). The area of life skills was picked up in RIATT recommendation 2, point 3 (see annex 2).

Free access to medical services for children and adolescents especially those who have no parental care was also highlighted as a key area of concern for the children (annex I, point 7) and the need for ARV programmes to go beyond mere provision of free ARVs and to include nutritional support (annex I, point 7) which resulted in the RIATT recommendation 1 point 3 (see annex 2).

The children emphasized the importance of ensuring that resources allocated for vulnerable children reach them (annex 1, point 8) and that there is follow up and action following the conference (annex 1, point 9). The children highlighted the need for follow up and that so often this doesn’t take place sufficiently and doesn’t involve the children.

There were distinctive successes in the conference and the overall consultation process. Important recommendations were made by the children, which directly influenced the final conference recommendations. Moreover, these were subsequently taken through to the GPF, where two adolescent delegates presented on behalf of the children and adolescents at the RIATT conference to the GPF delegates. However, it also brought to light the many ongoing challenges, issues and practices which need to be reconsidered when carrying out such a process and the need for “more work to be done with adults to enable them to accept the validity and potential of child/adult partnerships”.

The key lesson learned is that effective and meaningful child participation takes time, financial resources, patience and engagement of all involved including the adults!

7. Challenges

7.1 The preparation phase

Implementation in eight countries of a regional process: insufficient time, insufficient communication of the child protection guidelines and procedures, cumbersome administration, lack of commitment to child participation standards and guidelines

Implementation of any successful regional process requires certain good practices to be put in place. These include time to allow for nationalization of the process including contextualizing guidelines, nurturing national ownership and developing key relationships and partnerships with civil society organizations and government. The combination of the requirements for adherence to basic standards to implement an effective and meaningful child participation process, as well as a regional process were both not completely adhered to.

In the preparation phase leading up to the RIATT conference there were various challenges resulting in a lack of sufficient time available for the necessary preparation work to take place at a country level. Financial resources were not all in place before the process started, and slow institutional contract and funding procedures created delays. The process was not fully nationalized and developed at a national level. In some cases country teams felt the process was being imposed. This was due to the lack of time spent focusing on developing country led processes, “Where joint action is required, more time needs to be put aside to facilitate the process of joint action.”

Greater emphasis could be placed on strengthening cooperation between government and key participating civil society organizations at the outset and nationalizing guidelines into the specific country contexts. There should also be clarity regarding what happens if guidelines are not followed. The activity needs to be agreed in advance in a consultative manner with all partners and children and included in annual work plans. There were challenges to integrate the child participation consultations into existing national child participation processes in part due to the lack of strong structures facilitating this kind of process. Conferences can not compensate for national long term, sustained processes of child participation which are integrated into national structures and systems.

The results of the evaluation show that only 34% of the adult delegates agreed that the child participation processes during the conference were transparent, honest and accountable with almost half (48%) claiming they don’t know about these processes. It was stated that, “selection should be done in good time, parties involved in selection process should follow participation guidelines, some countries had hand picked delegates and that children with disabilities were not selected as child delegates for the conference.”

24. Ibid p. 12
An integral part of a child participation process is in the development of child friendly materials. These need to be developed in time. Such documents were not available in all participating countries. This created a challenge for the children to have an adequate source of information regarding the national situation and policies accessible to them. However, research papers were put in a child friendly format for the conference. This was carried out with the support of an experienced consultant who developed child friendly papers from the research papers that were available prior to the RIATT conference.

7.2 At the conference

Structure and delivery of the RIATT conference programme: dominated by adults, adult presentations not child-friendly, adults not respectful enough of children’s presentations, adults not prepared enough for strong child participation

During the conference although the child delegates made key speeches which significantly impacted on the adult delegates there were challenges in the interaction between the adults and children. Although most (95%) of the adult delegates in the evaluation felt that child delegates were given the opportunity to voice their opinions during the conference however, 16% of these also noted that it was difficult to ensure high quality participation and plenary sessions were rushed. On the whole, the adult delegates reported that the adults controlled the decisions and opinions of children during the conference (25%) and the children did not make decisions equally as adults during the conference (62%).

Half (50%) of the child delegates claimed that the speeches given by adults were inappropriate for the conference, with 12% of these commenting that “the speeches did not concentrate on present challenges and how to tackle them and that adult speeches were not child friendly.” Most (86%) of the children stated that the adult participants were attentive in the conference in general, but half of the children felt that the adult participants were not very attentive of what the children had to say. This reflects that although adult participants may have been fully engaged with the conference overall, they may not have been so equally engaged with the child delegates. Maybe the traditional set up of conference presentations and speeches needs to be re-considered and more creative methodologies used to allow children and adults to interact more successfully and easily.

There were also challenges for the children within the country team discussions. As Mr. Mwale, a child delegate from Malawi comments in the closing speech, “Some of our experiences here show that our participation in this conference has been greatly appreciated, but we have also had some experiences that have not been pleasant. While we made presentations in the main hall, everybody was aware that children are part of the conference but in the other presentations and sometimes in our country groups, we were completely forgotten.” He went on to say, “Some adults feel that we

27. Clacherty, G. RIATT Conference Child-friendly Conference papers in English and Portuguese
29. Ibid
30. Ibid
31. Hopeson, M. child delegate closing speech, p. 2 (found on the AIDS Portal www.AIDSPortal.org)
have been too aggressive, but let me tell you, every time we spoke in this conference, it was to convince you that we are aware of issues that concern us and not to confront or disrespect you." This emphasizes the need for further work to take place between children and adults before the conference at a country level and at the conference event in the process of sensitizing adults around child participation and how to listen and engage with children in an effective and empowering way.

It is clear that although huge efforts were made to ensure a smooth child participation process, the structure and delivery process of the conference programme should have in fact deepened and extended the child friendly methodologies of participation. This is also relevant regarding the participation of the older carers as in fact the conference needed to reconsider its structure and delivery in relation to more age-appropriate methodologies in order to enhance participation across all the different age groups.

7.3 What did children and adolescents feel about their participation at the RIATT conference?

As the RIATT conference came to an end, it was important to ask how the children and adolescents felt about the entire process, so that the learning could be used in planning similar opportunities in the future. Adult delegates were also asked to fill out a written questionnaire. Here is what some of the children and adolescents said during the evaluation:33

- Participation in other activities should be allowed during the conference
- There should be equal numbers of child delegates from each country
- Adults be prepared to interact more with children
- Children should not take the roles of adults
- Language used should be more child friendly
- Presentations should be more child friendly
- Adults brought cultural issues that did not allow effective interaction with children
- Some child delegates were not given chance to choose their chaperones

7.4 Child protection

Child protection is crucial for the success of any child participation process (including child participation in events) from the time of the children’s consultations in country through to the participation in the final activity. It touches on all aspects and people with whom the children may come into contact. The hotels, conference organizers and adult delegates at the conference all need to be aware of the child protection policies in place and how it is expected that the children will be treated. The role of chaperones is also key in taking care for the children during the stay. It is important that child

32. Hopeson, M. child delegate closing speech, p. 2 (found on the AIDS Portal www.AIDSPortal.org)
protection is carried out in the best interests of the children. As previously mentioned, the conference organizers followed clear guidelines in the implementation of the child participation process that had been adapted from the IATT Asia child participation working group. However, the process was still not completely satisfactory in relation to child protection measures being taken.

The child delegates were aware of the child protection policy, in the evaluation 95% of the children knew about the child protection policy for the conference before attending the conference. 90% of the child delegates also confirmed that they signed a consent form and understood why they were asked to do so, and 95% were happy with their chaperones. Parents and guardians also signed consent forms for the children prior to travel. The fact there was not 100% of the child delegates signing consent forms is due to the unplanned participation of two of the child delegates who arrived without consent forms. Only 53% of adult conference participants knew that there was a child protection person at the conference, and about 44% did not know either way34. It was also noted by Tamasha35 that more attention needs to be paid to the selection and preparation of chaperones. It became apparent that there were also challenges with the selection process of some chaperones due to being selected not purely based on the support they would give to the child.

The majority of the child delegates (80%) also reported that they were informed about the complaints procedure before they came to the conference but, only 5% of them reported that they were encouraged to express their concerns through the complaint procedure. However, more than two-thirds (64%) of the adult delegates said they did not know about the procedure, 28% confirmed by saying yes while only 9% believed formal complaints procedures were not in place.36 This indicates a lack of communication to the adult delegates about the child protection procedures in place for the children. Care should be taken to develop a protection plan with all institutions and staff in contact with the children involved such as the hotels and the design and application of the child protection guidelines should be age appropriate to balance with a child’s right for participation and freedom of expression.

### 7.5 Media presence at the conference

The presence of media at the conference was notable, especially at the Children’s Special session. It was noted that the media guidelines needed to be more comprehensive and include stipulations on what is and is not acceptable in terms of using the children’s images during and after the conference in producing reports, newsletters, magazines, films and web-based materials.37 There also needs to be closer attention paid to consent being obtained from the children, their parents, guardians and chaperones regarding use of images taken during the conference.

35. Mabala, R. RIATT Conference Children’s Participation Tamasha Report
37. The RIATT CPTT is developing recommendations on such stipulations, including on which exceptions are not applicable for obtaining age-appropriate informed consent and protection of children’s privacy.
7.6 Post conference challenges

One of the principal aims of the child participation process was to ensure that not only would the process respond to the objectives of the event, but that it would also serve as a vehicle to strengthen and promote ongoing networks of children, particularly those affected by HIV and AIDS at national as well as at regional levels. While this is yet to be fully evaluated, this may have not been so successful partly due to the difficulties that were faced around national ownership for the process in country, the lack of existing child participation structures/mechanisms in pace and the lack of engagement between the child delegates and adults before the conference. During the conference the level of interaction between the child delegates and their country teams varied and the importance put on child participation processes varied resulting in only some teams taking up the issue of child participation in their country action plans. There was also a lack of finances to cover the post conference events and a clear identification of which partner should take on a funding and co-ordination role. There has been some follow up in some countries for example in dissemination of the children’s key issues through local media. This echoes Mr. Mwale’s concern in his closing speech, “This conference has brought together so many important people, which convinces us that you are concerned about children. But we want to request you, that when you go back, please have the same commitment and the same will…To make all the recommendations that we have brought here today to become a reality.” In the recent child consultation process that took place for the World Congress III, a Brazilian adolescent made a similar comment, “Children, adolescents and youth are asking for answers, for action, because there’s too much being discussed and little action taking place.” Follow up and action after such international events is an ongoing challenge. The children and adolescents are calling for action and to be involved. Child participation in public fora and ongoing and structural national, community and district child participation still remains a gap in many countries.

8. Older carer consultation process

Alongside the child participation consultation process there was a similar process taking place in eight countries (Ethiopia, Kenya, Mozambique, South Africa, Tanzania, Uganda, Zambia and Zimbabwe) with older carers coordinated by Help Age International (HAI). A total of 19 focus group discussions (FGDs) were held in eight countries. Guidelines were developed for the FGDs which were conducted by partner organizations of Help Age International. The older carers selected a representative to take part in the RIATT conference (80:20 – female to male). Twelve older carers from the eight countries were selected by their peers to participate in the RIATT Children’s Conference.

Key issues for discussion in the FGDs included the challenges in providing care for orphans and vulnerable children (OVC) in relation to income support, livelihoods, education, intergenerational issues, psychosocial support; type of support which would enable caregivers to provide an enabling environment for OVC; awareness of rights, entitlements, benefits for OVC and caregivers and difficulties in accessing entitlements and benefits. Other key issues included the

awareness of voluntary counseling and testing and anti-retroviral treatment (ART) services, ensuring adherence to ART for children and the current nature and level of support being provided by the community, civil society and government in relation to UNGASS Indicator 10: Percentage of orphaned and vulnerable children aged 0-17 whose households received free basic external support in caring for the child.

In Mozambique the focus group discussions were held in Changara district of Tete province where HAI is implementing its programmes directly to the communities. Two districts were selected for the FGD. Cachembe has a total of 84 people living with HIV (PLHIV), 38 females and 46 males and Mesaawa 32, 18 females and 14 males. Both communities have associations of PLHIV, and these associations played an important role in organizing the discussions, particularly in the selection of participants. Responses to a question regarding suggestions on how programmes serving older people taking care of PLHIV and OVC can be improved include: livelihood support (food, shelter, clothing), micro-financing, water (more boreholes), monitoring and evaluation of programmes to verify if they are reaching PLHIV, animals for each of the orphans, livelihood support of orphans until they can stand on their own and livelihood support especially food and shelter. In response to a question regarding the challenges of taking care of a grandchild living with HIV, one of the issues related to the lack of free access to health care where the children still pay despite being orphans of PLHIV. Other concerns included the need for better nutrition, clothing, to sustain their schooling and psychosocial problems.

Overall findings from the country level consultations in relation to the older carers role towards the children they are caring for were presented at the conference by Kufekisa Langery representing the older carers. Examples included:

**Socio-economic challenges**

Older carers cited lack of regular income source as a major problem, resulting in a sale of assets and no time to do income generating activities because of their caregiving role.

Food insecurity is a problem due to poverty and older carers lack nutritious foods needed to support the children on treatment and to ensure the family remains healthy.

**Educational challenges**

Children often miss school because they are caring for their frail and sometimes sick grandparents.

**Health care challenges**

Adhering to ARV treatment for the children living with HIV is a challenge as the children are so curious and thus challenge the reason they are taking drugs.

Disclosing the HIV status to the child is a real challenge.

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39. HAI report on older carer consultation process in Mozambique
40. HAI report on older carer participation at the Children’s Conference
Caregiving skills

Many older carers said they lacked any training on basic home based care skills and thus felt they were not adequately supporting the children.

Where possible the older carers were represented at the country consultation meeting with the various country delegations. This was achieved in Kenya, Ethiopia and Mozambique. Where there were children’s consultations this supported the older carer consultation and facilitated the participation of the older carers in the country delegation such as Zimbabwe and Uganda.

In the conference session on recommendations and the way forward James Kwale, an older carer from Zambia presented the views of older carers:

- We need to keep the children under our care healthy and we also need to stay healthy so health services must be more accessible and responsive, including supporting us with those children who are taking ARVs
- Social protection systems and cash transfer programmes are vital to our welfare and that of the children we care for and we hope that they can be initiated and scaled up
- We do want to be self-reliant and stand on our own two feet as caregivers so programmes aimed at empowering us with skills, income generation and food security are also very important and should be part of national economic growth and poverty alleviation programmes
- Older caregivers need to receive training and on-going home-based care support to strengthen our care giving, parenting and counseling skills, which can also help us cope with sensitive issues on sexuality and disclosure
- Educational support programmes for the vulnerable children must continue and teachers and the education system need to be sensitive to the challenges older carers face in supporting the children’s education
- Finally, government and civil society orphan and vulnerable children programmes need to become more holistic and focus on supporting those in the family and community who are actually providing the care for the vulnerable children

Several of the conference recommendations, when addressed, will greatly strengthen the role of older carers and a number specifically targeted them:

1. Keep Parents and Children Alive
   - Expand the reach of vertical transmission prevention programmes for both women and men, and adopt a family centred approach, including older carers, to testing, treatment, adherence, counseling and support programmes.

2. Strengthen Families as a Unit of Care
   - Strengthen skills of child, youth and older caregivers with age and gender sensitive training, including life-and parenting skills, and awareness on sexuality and HIV and AIDS.
• Hire, train and adequately pay community health care workers to increase the accessibility of health systems to older carers and children, and linking them to needed services.

3. Increase Effectiveness of Services and Funding
• Improve regional and national data collection on vulnerable children and their carers by disaggregating by age and gender.

4. Human Rights for Vulnerable Children
• Reinforce the right to appropriate sexual and reproductive health education and information for children and older carers.

James Kwale’s expression of thanks to “be considered an equal partner in ’Making it Right for Children’,,” expresses the strong appreciation that the older carers had who participated in the conference. He went on to say, “We certainly have learned a lot about the impact of HIV and AIDS on children and how national governments, UN agencies and CSOs are responding. Hearing it from the children and participating in the conference with the children was a highlight of the conference for us.”

9. Some key lessons learned (and relearned) in the RIATT child and older carer consultation process.

Some Lessons learned

1. The needs of adult delegates are still prioritized over the needs of the child delegates in an adult-child conference.
2. Child participation advocates are not always listened to even when conference organizers have the best intentions of how to support and facilitate effective child participation.
3. Child participation takes time, patience, human resources, financial resources and if carried out in an effective way it needs to be fully integrated into the overall programme of activities.
4. It is not sufficient to give the task of child participation to a consultant group/ regional organisation and assume that this will be sufficient to manage the task, everyone involved in the activity in which there is child participation needs to be equally engaged and with a clear understanding and will to implement effective child participation mechanisms.

41. Kwale, James, older carer closing speech, RIATT conference (found on the AIDS Portal www.AIDSPortal.org)
Some lessons relearned from the RIATT conference example

Preparation

1. Adequate preparation time needs to be allowed for a successful child participation process. This includes time to nationalize the process, develop key partnerships, allow for contract and funding processes to be implemented and for the child participation activity to be included in work plans.

2. Regional consultation guidelines should be “nationalized” and adapted to different country contexts and there should be clarity regarding what happens if the guidelines are not followed. It is not enough to assume personnel working for an organization that promotes child participation and child rights will automatically follow the guidelines.

3. Child participation takes time and if guidelines are to be followed this requires time for the guidelines to be nationalized into the specific country contexts and for cooperation to be strengthened between participating organizations in country.

4. There needs to be adequate support from government and key civil society organizations at the outset in country for a successful regional child consultation process to take place at the country levels and opportunities for governments to be consulted with and to meet with the children before the event.

5. Child friendly documents need to be prepared in time.

6. It should be a principle that core funding has already been secured and arrangements in place for disbursement before initiating the process.

At the conference

1. The structure and delivery process of the conference programme need to be reconsidered in line with age appropriate methodologies of participation for children and older carers.

2. Child-adult sessions before the conference at country level and at the main conference are key in the process of sensitizing adults around child and older carer participation and how to listen and engage with children and older carers in an effective and empowering way.
**Child Protection**

1. Attention needs to be paid to the selection and preparation of chaperones. Even with guidelines and standards being set and followed up with there were still some cases where these were ignored mainly for organizational gain. For example organizations being determined to send staff members rather than a chaperone who would possibly better support the participation of the child.

2. Care should be taken to develop a protection plan with all institutions and staff in contact with the children involved such as the hotels.

3. The design and application of the child protection guidelines should be age appropriate to balance with a child’s right for participation and freedom of expression.

**Media**

Media guidelines should be comprehensive and include stipulations on what is and is not acceptable in terms of using the children’s images during and after the conference in producing reports, newsletters, magazines, films and web-based materials.

**10. Conclusion**

Child participation in events is important but only valuable if it strengthens ongoing structural child participation taking place at national, community and district levels. Child participation in national events could be encouraged which would also support and feed into child participation processes in regional events ensuring that children’s voices are represented in a fair way. The inclusion of older carers in consultation processes and conferences is important to highlight the issues that older carers face and encourage further dialogue and interaction between older carers and children and other key players.

Amongst the many challenges discussed in this paper there are clear examples of how the children’s and older carer’s consultation processes and participation in the RIATT conference made a significant impact on the other conference delegates. However, child and older carer participation in events will not be as effective as it could be unless child and older carer consultation processes are strengthened within national processes and that the culture within institutions is changed to create space for child and older carer participation to take place.
Annex 1 RIATT Conference Children’s recommendations and key issues

The main issues and recommendations that the child delegates presented in the RIATT conference on behalf of the 4000 children with whom they consulted.

“…the most important issues that we raised at the beginning of this conference were protection, participation, education, stigma and discrimination, health and systems and structures that do not work for children,” Mr. Mwale, child delegate from Malawi.

1. Child protection

*The need to strengthen child protection systems and structures for example in the area of protection from child abuse and property grabbing*

“Children are abused everyday and especially those who are living with guardians… children have no right to inherit their parents’ property, and even if they do have that right, the property is taken away by their relatives and the children do not know what to do and they have nowhere to go to get back their right.” Ms. Nhlapo, child delegate from South Africa.

2. Stigma and discrimination

*The need to address stigma and discrimination which are still very prevalent and have a major impact on the children’s lives.*

“In some areas, children living with HIV are seen as a curse and a burden to the people. Even now, some parents who do not know much about HIV still tell their children not to sit or play with other children who are affected by AIDS. Guidance and counseling alone does not stop stigma, because it is so deep in the community that when we know that we are affected or infected we just isolate ourselves,” Ms. Nhlapo.

3. Birth registration

*The need for free access to birth registration for all children.*

“…in some cases parents have to pay 4 dollars for it. Those four dollars can buy food! So why should I buy registration when I can buy food which I need and not the birth registration?” Ms. Nhlapo

4. Child participation

*The need to create effective and meaningful national child participation structures at the national, community and district levels.*

“The truth is that children never really participate and our views are not taken seriously. For instance, we have child parliaments that are not supported and even when we meet we end up talking amongst ourselves. Our issues are never added to the main issues that are discussed in the adult’s parliament,” Ms. Nhlapo.

“Above all, we need to always be involved in the processes that affect us not just for conferences like this one, but also for programmes about children in our communities,” Mr. Mwale.

5. Education

*The need to pay attention to the quality of the education.*

“Some classes have 70 children or more in one room, then there is no place to sit and so some sit on the floor. Many teachers are not qualified…*The identified gap in education support that secondary education is not free.*

42. Extracted from key plenary presentations made by child delegates in the RIATT conference (found on the AIDS Portal www.AIDSPortal.org)
"you are expected to pass and get to secondary school which is not free….. When I finish standard seven I am only 13 and I still need educational support. But I am forgotten until I am 18 and want to go to university. Then, I can get government support to study at university. Do I not exist between 13 to 18 years?” Ms. Nhlapo.

6. Life skills education

*The need to ensure that all children receive quality, in depth education on HIV and AIDS as well as life skills education*

“In schools, HIV and life skills education does not give us in depth information, and teachers have no way of getting updated information,” Ms. Nhlapo.

7. Access to medical services

*Access to medical services for vulnerable children and adolescents*

“In many places… medical services are only free for those who are 0 to 5 years, what about those between 10 and 18 years, who are orphans with no guardian, living in very poor conditions or those who are making life in the streets?” Ms. Nhlapo.

*The need for ARV programmes to address the issues of opportunistic infections and nutritional support*

“In some countries ARVs for children are provided but what about nutrition? ARVs can only help when someone has a good balanced diet,” Ms. Nhlapo.

8. Resources reaching children

*To ensure effective tracking of resources targeted for vulnerable children*

“…in some countries to be registered as an OVC or even to receive bursaries from the social welfare you must pay for it?… and there is no clear way to measure whether those who get the bursaries are the ones who need it the most,” Ms. Nhlapo.

9. Follow up and support

*The call to action for follow after the RIATT conference*

“This conference has brought together so many important people, which convinces us that you are concerned about children. But we want to request you, that when you go back, please have the same commitment and the same will…To make all the recommendations that we have brought here today to become a reality,” Mr. Mwale.

“…events like this conference are just events that come and go, how will we continue? How will we be supported to take back the information that we get here to our friends whose voices we carried with us? You have worked so hard to get us here; will you work just as hard to ensure that we are supported after this conference so that all children can benefit from it?” Ms. Nhlapo.
Annex 2: RIATT Conference Recommendations

RIATT Childrens Conference
“Getting it Right for Children”
Dar es Salaam October 2008

Recommendations for policy, programming, and funding for vulnerable children in Eastern and Southern Africa

We the delegates from 19 East and Southern African countries reaffirm the commitments made at the second United Nations General Assembly High Level Meeting on HIV/AIDS (UNGASS) to work towards universal access to prevention, treatment, care and support for children by 2010. Our Conference has benefited significantly from consultations and engagement with young people and older caregivers, both in the lead up to, and during our meeting. Here in Dar es Salaam we have actively promoted multisectoral and intergenerational dialogue between government, civil society, UN agencies, international cooperating partners, children and older caregivers.

This Conference followed regional meetings on Children Affected by AIDS in Lusaka (2000), Windhoek (2002), and Cape Town (2004). We recognise that significant progress has been made towards achieving the recommendations of these meetings particularly around planning national responses, treatment, prevention of vertical transmission, and resource mobilisation and allocation. However, much still remains to be done. The RIATT Children’s Conference delegates reinforce the urgent need for long term and predictable funding if universal accesses for children to treatment, prevention, care and support is to be achieved.

To this end, we recommend that the following actions be taken by governments, community and faith based organizations, the international community and regional bodies where appropriate:

1. KEEP PARENTS and CHILDREN ALIVE

   - Increase resource allocation to improve children’s access to early diagnosis, child appropriate treatment, child friendly voluntary counseling and testing, and supervisory and follow-up support for adherence.
   - Expand the reach of vertical transmission prevention programmes for both women and men, and adopt a family centered approach, including older carers, to testing, treatment, adherence, counseling and support programmes.
   - Link and integrate nutritional support into treatment programmes, and incorporate awareness of nutrition and positive living into support group activities for both adults and children.
   - Conduct research to understand how children are infected with HIV beyond vertical transmission, such as through sexual abuse and caring for sick family members.

2. STRENGTHEN FAMILIES AS A UNIT OF CARE

   - Gear relevant support towards the family, rather than only orphaned children because the large majority of them are cared for within a family context. Institutional care should be considered a last resort.
   - Cash transfers should be considered as a viable means of strengthening families’ capacities to provide care and support, and should be aligned to national policies and legislation relating to poverty and children.
   - Strengthen skills of child, youth and older caregivers with age and gender sensitive training, including life-and parenting skills, and awareness on sexuality and HIV and AIDS.
• Create formal structures and systems for effective and meaningful child participation at national, district and community levels. These structures should engage adolescent children in designing, implementing, and monitoring programmes that concern them.
• Support families with children under 5 through effective early childhood care and development programmes.
• Hire, train and adequately pay community health care workers to increase the accessibility of health systems to older carers and children, and linking them to needed services.

3. INCREASE EFFECTIVENESS of SERVICES and FUNDING

• Align all responses with the National AIDS Plans and National Plans of Action on “Orphans and Vulnerable Children” at all levels of government and ensure regional responses are aligned with plans of regional bodies.
• Ensure vulnerable children are included in national development and sectoral plans.
• Improve coordination between ministries and all key stakeholders providing services to children at national and district levels.
• Integrate social protection policies and plans into national development policies and plans. Strengthen national social welfare systems, with a focus on care and protection of vulnerable children including at the community level.
• Strengthen monitoring and evaluation mechanisms and encourage effective resource tracking from national to community level.
• Update regularly country situation analyses on vulnerable children to keep up with realities on the ground.
• Improve regional and national data collection on vulnerable children and their carers by disaggregating by age and gender.
• Emphasize the importance of civil registration systems, particularly birth and death registration in the legal protection of children.

4. HUMAN RIGHTS FOR VULNERABLE CHILDREN

• Include all vulnerable children in legislation, programmes, plans, and delivery of services, not just children orphaned and affected by AIDS.
• Define vulnerability at national, rather than international level, with inputs from children, older carers, and community and faith based organizations, to ensure that no vulnerable children are excluded or stigmatized. Vulnerable children can include orphaned and other children affected by AIDS, children affected by armed conflict, extreme poverty, and children with significant disabilities.
• Provide free good quality primary and secondary schooling and financing opportunities for tertiary level education, which include lifeskills. Support for transport, uniforms, and school materials must be provided.
• Incorporate issues of gender inequality, violence, and abuse particularly of girls into HIV prevention policies and programmes.
• Reinforce the right to appropriate sexual and reproductive health education and information for children and older carers.
• Strengthen and increase the number of child friendly courts and increase resources available for legal aid for children and older carers.
• Strengthen legal frameworks designed to protect children and ensure their timely implementation.
Annex 3: Useful publications on child participation


Practice Standards in Children’s Participation, International Save the Children Alliance 2005

12 Lessons Learned from Children’s Participation in the UN General Assembly Special Session on Children, International Save the Children Alliance, 2004

So you want to consult with children? A toolkit of good practice. International Save the Children Alliance, November 2003

UN Convention on the Rights of the Child, 1989

Children’s Participation: From tokenism to citizenship, UNICEF, Hart. R., 1992


The Evolving Capacities of the Child, UNICEF, Landsdown, G., 2005