

## HIV/AIDS: What about very young children?

### Introduction

The situation of very young children in HIV/AIDS affected communities is often overlooked. Fifteen per cent of orphans in Africa are aged 0-4 and 35 per cent are aged 5-9. Around one third are orphaned due to AIDS<sup>1</sup>. Initiatives to prevent mother to child transmission are showing some success<sup>2</sup>. Without intervention, the rates of mother to child transmission of HIV can vary from 15 to 30 per cent without breastfeeding and can reach 30 to 40 per cent with prolonged breastfeeding<sup>3</sup>.

Infants who are HIV positive have little or no access to anti-retroviral drugs (ARVs) and around half die before the age of one. Most of the rest die before the age of five<sup>4</sup>. WHO's 3 by 5 initiative, which hopes to provide three million people with ARV treatment by 2005, does not appear to be targeting this age group<sup>5</sup>.

Most very young children born to HIV positive parents spend their first few years with ill and tired caregivers. Under conditions of poverty, ill-health and stress, parents and other caregivers struggle to meet nutritional, health and psychosocial needs of young children at a critical formative stage. Very young children are often caregivers themselves, either to ill parents or other siblings. The lack of attention will have an impact on the quality of young children's current and future lives.

In programming there is an overt focus on orphans and vulnerable children and on preventing mother to child transmission. Much less attention is paid to those young children who are living with ill and dying mothers and fathers. HIV/AIDS and development strategies are inclined to provide services for older children and youth and ignore the very young age group<sup>6</sup>.

Recognising the lasting impact of both positive and negative experiences in the early years, some early childhood development organisations are starting to address the impact of HIV/AIDS on children under eight<sup>7</sup>.

### Key points

- Very young children are at a critical stage of development when holistic care and support is essential.
- Opportunities to meet young children's needs are greatly reduced in HIV/AIDS affected communities, yet HIV/AIDS research, policy and programming tends to ignore the 0-8 age group.
- Support for ongoing community initiatives can increase household and community capacity to provide holistic care for very young children affected by HIV/AIDS.
- Ways of listening to and consulting with very young children need to be promoted to enable children aged 0-8 to participate in processes that affect them and to be valued for the contributions that they make.
- National policy frameworks need to include HIV/AIDS in Early Childhood Development (ECD) programmes and integrate ECD initiatives into National AIDS plans of action.

### Significance of the early years

The early years are considered to be a critical stage in any child's development. The 0-8 period has a tremendous effect on the future health, cognitive development, cultural competencies and productivity of the individual<sup>8</sup>. An even more critical formative period is age 0-3<sup>9</sup>.

Young children who do lose either one or both parents to AIDS experience the traumatic illness and death of their parents. For young children dependent upon mothers this event can be even more significant. Bereaved and stigmatised, they are absorbed into extended families in which many primary caregivers are grandmothers whose situation is also often overlooked<sup>10</sup>. Where family wealth has been spent on 'cures' and treatment, the affected

families or caregiver are left impoverished. Under such conditions it is hard to provide the proper attention, stimulation, health care, nutrition and psychosocial support required for the holistic and optimal development of the child.

It is the most productive generation of 'breadwinners' that is dying from AIDS. The social, political and economic development of communities and nations<sup>11</sup> will also be affected as millions of adults grow up without the key skills and emotional intelligence<sup>12</sup> for survival, learning and socialisation. There are even possible links between poor early childhood experiences and a higher risk of HIV infection in later life<sup>13</sup>.

### Early childhood care and development

The UN Convention on the Rights of the Child (CRC) has universal application and all children between the ages of zero and eight are rights holders. Where states are morally and legally obliged to fulfil the rights set forth in the CRC the key areas of provision, protection and participation are critical. All children have a right to quality early childhood care and this should include access to health, nutrition, education, water and environmental sanitation in homes and communities, freedom from abuse and violence as well as enjoying growth and psychosocial development<sup>14</sup>.

The external environment has an impact upon the well-being and development of the child and balancing the needs and rights to survival and development is therefore a key element of supporting very young children. Participation, involving respecting and listening, is also essential in a holistic framework to ensure optimal early childhood development.

Children living with and affected by HIV/AIDS are very vulnerable and extra support is needed to ensure good early childhood care and development. Working with children under eight raises complex issues, the first of which is the varying stages of development that exist within this age range. Identifying the most vulnerable young children in HIV/AIDS affected communities may be difficult as many are not based in formal institutions such as pre-schools or schools.

As children under eight face increased health and developmental challenges in the context of HIV/AIDS, the nature of early childhood care is changing. Parents, caregivers and services providers need to know and understand the impact of HIV/AIDS on very young children. They also need support to provide the necessary holistic care<sup>15</sup>.

Attention to all children is important; fostering positive gender socialisation and gender sensitive

early childhood education is vital to reduce inequalities between girls and boys. This includes addressing patterns of learned behaviour among boys as well as girls. Girls are more likely to be adversely affected in early childhood due to discrimination and need to receive equal opportunities in terms of nutrition, intellectual stimulation and opportunity to play<sup>16</sup>.

Girls are also more likely to experience sexual and violent abuse, something that has been documented for older girls in schools in Africa<sup>17</sup>. In Southern Africa the prevalence of gender violence has led some to talk of a 'twin epidemic' of HIV/AIDS and violence against women<sup>18</sup>. In this context ideas that sleeping with a virgin cures AIDS places girls as young as six at risk<sup>19</sup>.

Other groups that tend to be overlooked in programmatic responses are disabled and nomadic children and children from religious and indigenous minorities. Understanding the social and cultural context and the existence of different groups within each setting will help to ensure that the most vulnerable children in HIV/AIDS affected communities are reached.

### Psychosocial support

The provision of psychosocial support is relatively new and is often overlooked in general ECD programming. This gap is therefore being highlighted in the context of how best to support HIV/AIDS affected young children. Psychosocial support is one way of increasing the capacities of young children and their caregivers to cope and improve development. Psychosocial support can be defined as providing the possibility of individual disclosure of feelings and emotions and expressions of personality (Psycho) combined with influencing the social environment to reintegrate affected children into their usual setting and encourage broader understanding of their specific situation (Social)<sup>20</sup>. Psychosocial support can build children's resilience within a wider supportive environment.

Developing a supportive environment for young children is crucial especially in HIV/AIDS affected communities where children may need time and space to rebuild, restore and re-establish relationships<sup>21</sup>. There may be lessons to learn from the situations of young children in conflict and refugee situations<sup>22</sup>.

One example of good practice is the Regional Psychosocial Support Initiative (REPSSI). One of its partners, the Salvation Army Masiye Camp runs 'life-skills' camps for orphans and vulnerable children under the age of five and their caregivers. The children are engaged through counselling processes and play.

**All young children have the right to quality early childhood care**

Talking about issues like death and HIV/AIDS status of parents and children to very young children can be difficult. Caregivers should be able to access counselling and training on caring for children, children's rights and preparing a memory book. Other examples of good practice are the use of psychosocial manuals at grassroots level<sup>23</sup>.

ECD educators are also reaching very young children by drawing on the US children's television series *Sesame Street*. The South African version *Takalani Sesame* raises awareness and destigmatises HIV/AIDS through an HIV positive five-year-old puppet called Kami<sup>24</sup>.

## Programming in the community

Families and communities are the first line of response to the impact of HIV/AIDS on very young children. Often communities in developing countries are seen as strong enough to endure any obstacle, but in broad-scale situations of poverty, coping mechanisms are strained to breaking point and traditional safety nets unravelling<sup>25</sup>. Alternatively, Williamson notes the danger of recent negative media reporting on the lack of community capacity in Africa. Failing to recognise actual responses people are making on the ground makes it harder to convince US donors of the importance of strengthening household and community capacities<sup>26</sup>.

When young children are orphaned, there is a continuum of formal to informal care options from statutory residential care to voluntary support in the community and informal fostering<sup>27</sup>. A predominant response has been to care for children in residential institutions such as orphanages which are expensive to run, are unavailable for the majority and do not encourage positive early childhood experiences. Experiences in institutions can result in attachment problems with long-term impacts. Children are not integrated into society and find it difficult to re-enter upon leaving<sup>28</sup>. In addition, orphanages tend to undermine traditional care giving systems such as extended families, which should be strengthened and supported.

A major impact of HIV/AIDS is that caregivers of very young children, whether they are parents, grandparents or extended family members are pushed to financial and practical limits. Caregivers in communities affected by HIV/AIDS therefore need supporting. This can be done in multiple ways: through counselling and training in parenting skills, burial and lending credit associations, agricultural and shared childcare projects<sup>29</sup>. Children under eight are in diverse circumstances. Children of school-going age may need assistance to attend pre-school

or school. Other children may need nutritional support or help with finding alternative care.

Where intervention does take place there should be a strong emphasis on understanding and engaging with the cultural context of the community and society<sup>30</sup>. Community based care should reflect the culture and values of the families and communities and support existing coping mechanisms families are using. It should identify who is carrying out the basic tasks of caregiving and protection while considering the availability of local resources<sup>31</sup>.

Existing areas of programming that have the potential to reach out to children under five are home-based care and home visiting programmes<sup>32</sup>. Volunteers and caregivers can monitor the condition of young children in households, identify and respond to children's needs and link with community resources. Assessment of the situation of very young children is key and tools to do so are starting to emerge<sup>33</sup>.

TREE (Training and Resources in Early Education) in South Africa trains women to establish early childhood education programmes in communities affected by HIV/AIDS. This approach includes needs analysis of young children, counselling, identifying community resources, and helping to choose guardians. It may be a more scalable means of addressing the needs of very young children<sup>34</sup>.

Existing services for children such as health services can be encouraged to focus on children under eight. Reaching young children could also be achieved through current AIDS programmes dealing with PMTCT<sup>35</sup> which then aim to protect and support children who do not have HIV.

Working with families and communities in a way that respects cultural values and builds local capacity to cope is challenging. There is no one definition of family and there is no one model of family support<sup>36</sup>. There is a need to recognise the diverse character of households and 'family' set-ups where parents are ill or have died<sup>37</sup>. Directly intervening in the household sphere raises ethical questions about the appropriate limits of development interventions aimed at groups such as very young children and their caregivers. Leaving poor households to face the effects of prevailing global political and economic forces also presents ethical issues. Interventions that target the detail of household and community life need to be balanced with a broader empowerment agenda that would develop the capacity of people and young children to better negotiate their choices and responsibilities.

## Communication and young children

Although support for caregivers is a vital part of creating the holistic environment of early childhood

**HIV/AIDS programmes should support the coping mechanisms families are already using**

care, there is a danger that programming for children under eight leaves young children out of planning, implementing and evaluative processes. One way of avoiding this is to focus on the act of caregiving rather than the caregivers themselves. Visibility of children varies across cultures and households within cultures, but it remains unusual for very young children's voices to be heard. This is especially the case in communities with a culture of deference to authority where the strongest adult voices are heard. A unique and innovative project in Kenya called Speak for the Child is specifically addressing the needs of children under five in an HIV/AIDS affected community. However, as the project case-study notes even here during a PLA exercise participants and facilitators did not immediately focus on the young children themselves<sup>38</sup>.

Alderson discusses the many implications when including very young children in planning, implementing and evaluating processes, while recognising it is vital that their right to participate is respected<sup>39</sup>. Programming needs to take into account that 'children are experts in their own lives'<sup>40</sup>. Listening is a reflective practice and a social transaction that enhances the well-being of very young children. Children need to be listened to and adults need to take what children say seriously<sup>41</sup>. Given that very young children are unable to analyse situations or express themselves in the same way as older children, appropriate ways must be found to include them.

Work carried out in the UK using multi-sensory approaches aimed at identifying a view of the world according to very young children could be drawn upon to develop approaches elsewhere<sup>42</sup>. Challenges arising from consulting with and listening to children in different ways have been encountered in work carried out with disabled children where 'listening on all channels' becomes vital<sup>43</sup>. Methods like mapping and tours already have their roots in international development and participatory approaches<sup>44</sup>. Community development has previously involved older children<sup>45</sup> and focusing on younger children would be a further step.

Listening works in socially inclusive relationships. As Lancaster says, 'it is about power sharing'<sup>46</sup>. Despite increasing attention to power differentials in development, the childhood context is less well explored. Questions remain about where appropriate authority between caregivers and children begins and ends. Links to wider patterns of social authority, such as gender, ethnicity and class are not well understood in the North or South<sup>47</sup>.

Children are experts in their own lives: adults need to take what children say seriously

## Policy responses

There is a general need to increase the supply of ECD support programmes at family, community and service provision levels. National ECD programmes should be an integral part of all macro-level National Development Strategies<sup>48</sup>.

National and international policies and legislation should be developed to explicitly protect and support the 0-8 age group. Some suggest that rather than separate policies for the 0-8 age group, policies need to be developmentally sensitive and address the particular needs of each age group. All age groups should be addressed in differentiated national policies and programmes<sup>49</sup>.

Then there is a more specific need to address holistically HIV/AIDS issues for very young children<sup>50</sup>. All ECD programmes in countries with a high prevalence of HIV/AIDS need to integrate ways of catering for the specific experiences of very young children and caregivers in HIV/AIDS affected communities.

National AIDS Councils are not overtly engaging with 0-8 year olds and their effectiveness would be enhanced by an ECD focus. International, national or local NGOs that have an HIV/AIDS children or youth element could ensure that very young children are included in their strategies<sup>51</sup>. In 2003 UNAIDS, The World Bank and UNICEF published 'Operational Guidelines for Supporting Early Childhood Development (ECD) in Multi-Sectoral HIV/AIDS Programmes in Africa', which is a useful tool for decision-makers and policy planners. The guidelines give direction on how to integrate effective broad-scale interventions to ensure the healthy physical,

emotional and cognitive development of young children. This 'should be an essential component of any well designed, integrated national program to prevent and reduce the impact of HIV/AIDS'<sup>52</sup>.

UNICEF experience suggests that a good ECD HIV/AIDS programme should have a broad framework, be developed with and for families, and with and for communities respecting cultural values and building local capacity. Also important is equal access for all children and a programme that is flexible and reflects diversity<sup>53</sup>. There should be great sensitivity to avoid causing stigma and further discrimination of children and families that are affected by HIV/AIDS. It should also take into account the different experiences and needs of the different age groups within early childhood. Addressing children aged from zero to three who are entirely dependent upon their primary caregivers and others will require a different response to working with children aged from four to eight, some of whom are at school or are part of the labour market<sup>54</sup>.

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## Conclusions

Very young children are at a crucial stage of personal development and need holistic care and support from caregivers, older children and other community members. Living in HIV/AIDS affected communities reduces opportunities to receive such care and development and to be recognised as key contributors and agents. Increasing household and community capacity to care for very young children affected by HIV/AIDS through sustainable community initiatives is a logical step. Services can be improved by listening to young children and encouraging their participation as part of everyday processes. Advocacy to get very young children on local, national and global agendas will be critical to include HIV/AIDS in national ECD programs, to include very young children in National AIDS Plans and to promote access to ARVs. Support needs to come through the international community, state welfare and education subsidies and public private partnerships<sup>55</sup>. Media advocacy on behalf of very young children plays a key role in promoting positive messages to reduce stigma and discrimination and encourage good funding practices<sup>56</sup>.

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**Findings** give snapshots of current research and debate in key areas of health communication and development. Findings aim to inform development practitioners and policy makers and to stimulate critical reflection.

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