



# **Adolescents Living with HIV:**

## **Developing and Strengthening Care and Support Services**

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# Adolescents Living with HIV:



## Developing and Strengthening Care and Support Services

Commissioned by the UNICEF Regional Office for Central and Eastern Europe and the Commonwealth of Independent States (UNICEF RO CEECIS)

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## FOREWORD

In 2015, an estimated two million adolescents (10-19 year olds) were living with HIV worldwide and every hour an estimated 26 adolescents were newly infected with HIV.

Adolescents living with HIV have mostly the same dreams and hopes as all other adolescents. Although they often face a number of health challenges in their day-to-day lives, many of the issues faced by adolescents living with HIV are linked to broader psycho-social aspects of their lives. In many ways, their experience of living with HIV provides the best guidance on how to support them to realize their rights and their full potential.

The continuing high rates of new HIV infections and growing AIDS mortality among adolescents suggests that a change in adolescent programming is required. The voices and concerns of adolescents and young people need to be heard by care providers. Youth-centred and youth-led approaches that engage young people in the planning, implementation and evaluation of programmes are needed. Policy makers should put more effort into understanding the distinctiveness of adolescence in the context of HIV and make longer term commitments to funding and programme support. There is an increased need for capacity building and trained staff. The “All In” initiative launched by UNICEF and partners to end adolescent AIDS provides a platform for dialogue with young people, policy makers, care providers, community leaders and other stakeholders for action supporting adolescents.

This handbook, with inputs from leading experts who have trained hundreds of professionals, provides indispensable tools for strengthening the management and care of adolescents living with HIV. Clinicians and social workers are provided with step by step guidance on how to work with adolescents and parents and increase their skills-sets to help them engage with and retain adolescents living with HIV in support services. It describes the challenges of working with families and care givers, promotes holistic models of child-centered assessment and practice, communication with families and children, with a focus on naming HIV, promoting adherence to treatment and ongoing conversations and supportive dialogue involving HIV positive adolescents as partners and leaders in their own care.

Designed for optimal learning, the handbook allows to choose written, oral, visual, individual, and group strategies that best suit different learning styles. This handbook is about adolescents and it is for professionals who work with them. It is meant to be a living document that adapts as new information and evidence emerges and it hopes to support professionals to build their confidence, skills and better connections with adolescents living with HIV.

UNICEF HIV Team

## Definitions

Adolescent	Aged 10-19 years of age.
Parent	Biological parent, step-parent, or adoptive parent.
Carer	Person who is primary carer of the child, but not their parent. This can be someone who is a legal guardian, such as a family member or state provided carer, such as a foster carer.
Young adult	Aged 19-25 years of age.

## Acronyms

<b>ART</b>	Anti-retroviral therapy
<b>ALHIV</b>	Adolescents living with HIV
<b>CEE/CIS</b>	central and eastern Europe and Commonwealth of Independent States
<b>CHIVA</b>	Children's HIV Association for the UK & Ireland
<b>C&amp;ALHIV</b>	Children and adolescents living with HIV
<b>UNICEF</b>	United Nations Children's Fund
<b>UNCRC</b>	United Nations Convention on the Rights of the Child
<b>WHO</b>	World Health Organization

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## INTRODUCTION

### The global context

This handbook has been written for practitioners working directly with C&ALHIV and for policy makers and management to help develop services and protocols. To that end, it includes policy and practice guidance for the development of services, practice models and practical examples. The global experience of HIV offers many shared elements and this handbook reflects these, setting out practical guidance and tools that can be used in different settings.

Commissioned by UNICEF Regional Office for CEE/CIS as part of a wider project to assist the development of support provision for C&ALHIV in that region, this handbook has been produced by experts from the UK who have worked with children, adolescents and families living with HIV for almost two decades.



This resource aims to:

- Share knowledge and learning from practice developments in the UK that can be useful in a global context
- Ensure practitioners have a broad understanding of the psychological and social impacts of HIV on childhood and adolescence
- Promote the development of support that responds to the holistic needs of the child and adolescent
- Promote professional responses to reduce the impact of HIV stigma on children and adolescents.

The handbook promotes multi-disciplinary working as the best approach to addressing the physical, psychological and social impacts of HIV. A robust partnership between health and social care services ensures a collaborative approach, where a flow of communication between practitioners exists and services are working together

to meet the needs of the child, adolescent or family. It also acknowledges throughout that HIV disproportionately affects more vulnerable social groups and that this should be reflected in the practice that is developed.



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## Adolescents and HIV

There are approximately 1.2 billion adolescents in the world, over 80% of whom live in the developing world and an estimated 2.1 million adolescents were living with HIV in 2012 (UNAIDS, 2013). [1]

In 2014, the WHO produced *Health for the world's adolescents: A second chance in the second decade* [2] which stated that over the last decade, HIV had become one of the biggest killers of the world's adolescents, second only to road traffic accidents. As global HIV rates decline and the prevention of mother-to-child transmission is being heralded as a global triumph, these findings clearly showed that ALHIV had been overlooked.

Adolescence is the transition from childhood to adulthood and a time when the child moves from dependence towards greater independence. At this time children begin to gain a sense of autonomy and a desire to establish their

individual identity. Friendships and the peer group, and 'fitting in' with peers, can become increasingly important. Adolescence is known as a time of risk taking and experimentation.

It is typical for an HIV diagnosis to be surrounded with secrecy for many groups of people who become infected. For children and adolescents who have grown up with HIV, HIV is closely linked to their sense of who they are, as it has always been a part of them. As such, secrecy and HIV can become interlinked and for many C&ALHIV, this means they keep part of themselves a secret.

HIV remains highly stigmatised and for many HIV positive people there is frequently a fear of other people finding out. This can build a negative experience of having HIV, as it becomes viewed as shameful, emphasising difference. These negative associations can be internalised, and for the adolescent who is struggling

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to work out who they are, the negative social responses to HIV can lead to a profound experience of self-stigma. This can reinforce feelings of difference, isolation (particularly from peers) and being of less worth than others.

Poor adherence and engagement in clinical care during adolescence is normal for all health conditions. The common perception of HIV being associated with an imminent death and limiting opportunities can lead to

ALHIV becoming fatalistic and so their risk taking behaviour may be seen as more extreme than their HIV negative peers. ALHIV often experience low self-esteem and struggle to see a future for themselves. But adolescence is also a time of opportunity and creativity and it is important to remember that adolescence is a transition period that may be turbulent, but it will end.

### The UN Convention on the Rights of the Child (UNCRC)

The UNCRC is referred to throughout this resource. It was produced in 1989 and to date has been ratified by 192 countries (although some countries have placed reservations on some articles). The UNCRC is the basis for child-centred and child rights approaches.

This Convention sets out the basic rights of children under 18 years without exception or discrimination of any kind, stipulating that the best interests of the

child must be the primary consideration in all matters affecting children (Article 3); that children's survival and development must be ensured (Article 6); and that children have the right to participate in decisions that affect them (Article 12).

Within the context of children with health conditions, the UNCRC offers certain articles that are particularly pertinent for C&ALHIV:

- Every child should have access to information and material from a diversity of national and international sources, especially those aimed at the promotion of his or her social, spiritual, and moral well being and physical and mental health (Article 17)
- States parties recognise the rights of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. States parties shall strive to ensure that no child is deprived of his or her right of access to such healthcare services (Article 24).



## WHO guidelines for C&ALHIV

This handbook has been influenced by practice experience and research and is closely linked with some key WHO publications.

WHO (2011) *HIV disclosure counselling for children up to 12 years*. This guideline presents research which concludes that children's health and well-being is supported when they have access to open conversations about their health and where HIV is named to them. The guideline's recommendations state that, '...children of school age should be told their HIV positive status: younger children should be told incrementally to accommodate their cognitive skills and emotional maturity, in preparation for full disclosure' [3].

This handbook upholds this recommendation, promoting C&ALHIV

having full knowledge about their HIV status, which then enables work to take place to support them living well and challenges wider stigma towards HIV.

WHO (2013) *HIV and Adolescents; Guidance for HIV testing and counselling and care for adolescents living with HIV*. This guideline considers operational approaches and different options of response to the needs of adolescents with HIV. It provides a range of practice examples which illustrate different responses to the needs of adolescents with HIV, and offers practice guidance.

This handbook sets out to provide support in meeting the key recommendations from this WHO (2013) guideline, that:

- Adolescents should be counselled about the potential benefits and risks of disclosure of their HIV status to others and empowered and supported to determine if, when, how and to whom to disclose
- Community-based approaches can improve treatment adherence and retention in care of adolescents living with HIV
- Training of health-care workers can contribute to treatment adherence and improvement in retention in care of adolescents living with HIV [4].

Section One has been written by Dr Caroline Foster and offers a medical perspective, setting out the health needs of ALHIV. Section Two explores in detail different psychosocial impacts on C&ALHIV, to support an in-depth understanding of the lives of these children. Section Three looks specifically at those adolescents who acquire HIV behaviourally. Section Four sets out

child-centred HIV specific approaches to developing practice and politics. Finally, Section Four offers examples of peer support group work from the UK.

The appendices include numerous examples of activities that have been run with C&ALHIV, to explore HIV specific issues in peer groups and one-to-one sessions with workers.





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## SECTION ONE: CLINICAL ISSUES FOR ALHIV

Dr Caroline Foster  
Consultant in Adolescent Infectious Diseases/HIV

*Watch video: The impact of psychosocial needs on health provision - <http://vimeo.com/112460123> (password: chiva)*

In regions of the world where ART is available, perinatally acquired HIV-1 infection is now a chronic disease of childhood [5]. High uptake of antenatal testing, reduced mother-to-child transmission rates from diagnosed women, improved survival following ART and later age at presentation among those born abroad [6] mean that the average age of perinatally infected children in many European cohorts is now over 13 years. Increasing numbers

of ALHIV are therefore transitioning from paediatric to adult services and join the large numbers of ALHIV infected through sexual transmission [7]. This means that children are surviving into adulthood, yet the process of growing up with HIV can present clinical and psychological complications, not all of which are directly HIV related. Some key clinical issues faced by this group are outlined below.

### 1.1 The brain and neurocognitive function

Whilst the importance of brain growth in infancy is well established, there is increasing recognition of the enormous changes that occur in the adolescent brain. At 11-12 years, brain function slows

in preparation for increased synaptic proliferation (frontal lobe) then pruning and strengthening of neural pathways that continues into our mid-twenties. During adolescence, the thalamic drive

for 'reward' may be mismatched with later development of executive functioning 'reasoning' and may explain why risk taking behaviour is much more common in adolescents.

Whilst ART has had a remarkable impact on long-term survival for children born with HIV, the long-term effects of living with HIV and prolonged exposure to antiretroviral therapy throughout post-natal growth and development are becoming apparent. Data is now emerging regarding neurocognitive development, mental health and cardiovascular and bone toxicity, the longer-term outcomes of which remain uncertain.

Perinatally acquired HIV occurs in the context of an immature brain with human brain development typically continuing into the third decade of a person's life. Without antiretroviral therapy, around

10% of infected infants present with progressive severe HIV encephalopathy (damage to the brain), which although arrested by ART, leaves residual cognitive and motor deficits with significant impact on independent mobility and daily living. Increased rates of expressive language delay and behavioural difficulties are reported in preschool children and more subtle educational difficulties become more apparent in secondary school aged children.

Whilst mental health issues are more common in adolescence when compared to earlier childhood in the general population, increased rates of psychological disorders and psychiatric diagnoses, most frequently anxiety and depressive disorders, are reported in ALHIV, impacting on quality of life and on adherence to ART [8].

## 1.2 Adherence

Adherence to antiretroviral therapy appears to be poorer during adolescence for all ALHIV, although a similar pattern is seen in other chronic diseases of childhood. ALHIV often face multiple barriers to adherence including structural barriers in fitting medication into complex patterns of daily life, low expectancy for outcome of antiretroviral therapy and mental health/substance abuse. The impact of HIV as a family disease means that some adolescents have suffered bereavement, losing parents and other family members to HIV, further impacting on health beliefs and adult support networks around adherence.

Early patterns of adherence on initiating ART predict the long-term adherence of HIV positive children, which means that time spent by a multidisciplinary team in preparation and education prior to initiation of therapy, and switching regimens, including the use of peer mentors, counsellors and NGO support are extremely important. Adherence messages need to be frequently repeated as medication fatigue occurs and particular attention given during the period of transition from paediatric to adult services, a time often associated with poorer attendance and adherence to medication.



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Despite recent advances in co-formulations, smaller tablet sizes and multidisciplinary approaches to adherence, a small proportion of adolescents continue to either adhere very poorly or decline antiretroviral therapy despite severe immune suppression with its risk of opportunistic infection and death. Keeping this group engaged as they grow towards

adulthood is extremely important, as those who choose not to, or are unable to take treatment, require ongoing support and education, including access to sexual health services to prevent onwards transmission to sexual partners and their offspring. This area is expanded further in Section Two: Managing HIV during adolescence.

### 1.3 Relationships and sexual health education

The earlier discussions begin, relating to sex and relationships, the easier this is for the child, practitioner and parent/carer. Begin with an explanation of the physical and emotional changes that occur in boys and girls during puberty, emphasising that these are normal changes.

In many countries sexual health education is part of the school curriculum, often occurring around the age of 12 years. However, the quality and retention of such information is extremely variable and ALHIV need specific information

that is relevant for their unique situation. Encouraging the younger adolescent to have a small part of the consultation alone with the doctor/nurse supports these discussions. When they are familiar with this pattern of care, it allows opportunity for discussion, education and questions that adolescents may not wish to ask in front of their parent/carers, either because of embarrassment or because they worry about asking difficult questions that may upset their parent/carers.





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Adolescents need simple, basic, clear, age-appropriate facts, explained in language they understand, given in small volumes and repeated frequently. Information should be generic; try to avoid making assumptions based on whether you think a young person is or is not sexually active – we often know very little about their lives. Do not presume relationships are heterosexual; up to 10% of young people experience same sex relationships at some time and using the word 'partners' until a young person has clarified their current sexual orientation avoids confusion.

Consistent condom use should always be encouraged, with additional contraceptive methods discussed with

adolescents. Recent research has shown that the risk of sexual transmission of HIV is substantially reduced where the HIV positive person has an undetectable viral load [9]. Typically suppressive ART reduces HIV viral loads in semen and cervico-vaginal fluid as well as plasma. However, occasional individuals have been shown to have detectable levels of HIV in genital secretions *despite* virological suppression in plasma, because of compartmentalisation of HIV within the genital tract. For this reason, and because a viral load reflects only one time point and other Sexually Transmitted Infections could be present, health professionals continue to recommend condom use with ALHIV.

#### 1.4 Onward disclosure of HIV

Whilst much attention has been paid to the process of naming HIV to a CLHIV, processes of supporting onward disclosure to family, friends and sexual

partners have received less attention. However, as the perinatal cohort ages and much larger numbers of children enter adolescence, there is a need for



similarly robust processes to support them through onward disclosure.

Many ALHIV have not disclosed their status to anyone and separate their life into compartments: their HIV life and their daily life. There is some evidence that self-

disclosure may improve psychological wellbeing for some adolescents, which subsequently enhances their physical health, but there are also examples where outcomes have been less positive.



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Some adolescents want to disclose their status to close friends, relatives and to sexual partners. It may be helpful to talk through this process: the advantages (becoming closer, sharing, not living a 'double life'), but also the potential disadvantages (rejection, anger, and wider disclosure of their status and possibly other family members). This is expanded further in Section Two: Managing HIV during adolescence.

In some countries, transmitting HIV to your partner, even unintentionally, is a criminal offence and people have been prosecuted and received lengthy jail

terms. Professionals need to be aware of the law in their own country so they can give sensitive, accurate guidance to ALHIV. It is important that these discussions empower the ALHIV with facts rather than fear. Talk through the detail simply and ask them to reflect back what they understand. If an ALHIV is going to travel, they will need to consider the legal position regarding onward transmission of HIV in the countries they visit.

## 1.5 Transition to adult care

### Transition has been defined as:

*'the planned purposeful process that addresses the medical, psychosocial and educational/vocational needs of adolescents and young adults with chronic physical and medical conditions as they move from child-centred to adult-oriented health care systems.'*

Increasing numbers of perinatally infected ALHIV are entering adult care and the age at which this occurs varies markedly across the globe, from 12 years in parts of sub-Saharan Africa to 24 years in regions such as the US where there is dedicated adolescent/young adult services.

With other chronic diseases, transition programmes have been shown to improve attendance, disease control, self-management and patient and carer satisfaction. Conversely, direct transfer to adult services has been associated with poorer attendance and adherence, resulting in increased disease-related mortality and morbidity. Thought and planning must go into this process to ensure the best outcomes for the adolescent and to ensure they remain engaged in care. See Appendix Two: Further Reading for resources relating to this.

### Conclusion

Caring for ALHIV can be complex. HIV or the social situation the adolescent lives in can present difficult psychosocial issues that can impact on their engagement with health and how well they are able to self-care. There are worldwide examples of excellent support that provides a safe place for ALHIV who know their HIV diagnosis, to meet others and to share concerns. As the ALHIV often presents multiple non-health issues, multi-disciplinary teamwork is essential in providing a coherent package of care.

Adolescence is a time of enormous change, much of it exciting although some challenges have to be negotiated. A chronic disease adds to the complexity of this period of life, and one that is stigmatising and sexually transmissible even more so. However, the success of ART in the last 15 years means that increasing numbers of children born with HIV have an optimistic long term future and require careful, coordinated, adolescent-centred multidisciplinary support to fulfil their potential as adults within society.

*Watch video: Developing youth-friendly HIV services - <http://vimeo.com/112460122> (password: chiva)*



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## SECTION TWO: THE PSYCHOSOCIAL NEEDS OF C&ALHIV

This section explores specific issues that HIV can present for children, adolescents and families. It focuses on the psychosocial impacts and support needs of C&ALHIV, and does not include access to health care and medication, which may be an issue in different contexts.

For many C&ALHIV and their families, HIV is one of a multitude of issues they face, and at times the other issues - such as having sufficient food, housing, substance misuse, mental health problems - may be more critical. Wider

social issues are not included in this section, but need to be acknowledged, and where possible addressed. A holistic approach should always be taken when supporting C&ALHIV, and these wider issues taken into account, as they will impact on all aspects of the child's life including engagement, adherence and health outcomes.

Group and one-to-one activities that can be used to address some of these issues can be found in Appendix One.

This section covers the following areas:

### 2.1 Growing up with HIV

- Talking openly about HIV
- Children fully understanding HIV
- Parental bereavement
- Children growing up without their biological parents.





## 2.2 Managing HIV during adolescence

- Isolation
- Stigma and self-stigma
- Taking medicine
- Sex and sexuality
- Talking to others about HIV
- Having no home.



## 2.3 HIV and the family context

- How HIV was acquired
- The family
- Caring responsibilities for parents and/or siblings
- Drug use in the family.

## 2.1 Growing up with HIV

### Talking openly about HIV

This area is covered in some detail in Section Three, but it is important to examine the role of professionals in addressing this issue. At the start of the HIV epidemic, when children were not expected to survive into childhood, not telling them their diagnosis was seen to protect them. The advent of ART and HIV becoming a manageable chronic health condition means the prognosis for children born with HIV is hugely improved, with the expectation that with access to ART, children can live long into adulthood.

There have also been developments in understanding children's rights and

having this approach embedded in professional responses to children in settings such as health and education. This has generally led to child-centred approaches to caring for children with health conditions, involving them in decisions about their own health care, taking their views into account and seeing them as competent in doing this. Children who are given clear, simple information about their health are seen to have less fears, increased understanding and improved outcomes.

With respect to the above, HIV is far behind other health conditions. It is not uncommon for C&ALHIV not to be told

HIV is the virus they live with, or that they are only given partial information. When HIV is eventually disclosed to them, it

can remain an area of some anxiety and concern.



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It is critical to consider how children are engaged in conversations about their HIV as this will have a significant impact on how they understand and accept their diagnosis. Professionals have an

important role to play in addressing the stigma that surrounds HIV through the active encouragement of, and engagement in, open conversations about HIV.

### Children fully understanding HIV

Having a clear and accurate understanding of HIV is essential to empowering C&ALHIV to live well and develop a good relationship with their medical condition. This needs to include a clear understanding of HIV as a virus, how it replicates and how it compromises their immune system. This knowledge will also mean they understand how their medication works and how to keep themselves well. Equipping C&ALHIV with this knowledge will empower them, giving them control and responsibility over their own health.

Although HIV may be explained to C&ALHIV in a clinical setting, it is important that there are ongoing opportunities for conversations in other settings. Exploring the information in different ways offers multiple opportunities to ask questions and express any confusion or uncertainty. Clinics can feel like formal spaces for C&ALHIV and some may find it more difficult to ask questions in this setting.

Experience of work with this group has shown that C&ALHIV respond well to receiving this information in youth-

friendly, engaging ways. Repeating information is important as often a child will take away the part of the information that is relevant to them at that time, so revisiting information regularly in different ways will provoke further discussion and debate. Active and participatory approaches to learning (as opposed to presentations of information)

are also known to be particularly effective with children. Peer support sessions are good places where C&ALHIV can safely explore issues and ask questions. Never presume knowledge and understanding, and always get the child or adolescent to reflect back what you have been talking about to ensure they have properly understood.

### Parental bereavement

One of the most significant things that can happen to a child is the death of a parent during childhood. This loss has a serious impact on any child, but in relation to HIV, it presents additional complexities. If the parent has died from AIDS related illnesses, the C&ALHIV could believe they will experience the same outcome. If the parent has died before the child was told their HIV status, when HIV is finally named they will be learning the truth about their parent's death and again potentially relate this to what they perceive to be their imminent death. This link between HIV and death can bring a sense of fear and anxiety, compounding feelings around 'being lied to' and possibly having to keep this family secret from siblings and other family members.

When supporting C&ALHIV, it is important to carry out holistic needs assessments (see Appendix Five). This will enable bereavement to be highlighted and will assist an understanding of the impact on the child at that time and in the future. Open and honest conversations can help, offering the space to talk and ask questions as and when the child needs to.

Group work can support the ALHIV to find the language to express themselves and be able to say how the death of their parent has affected them. It also offers the opportunity to share these experiences with others who have had a parent die, acknowledging that they are not alone in this experience.

### Children growing up without biological parents

It is not uncommon for C&ALHIV to grow up in environments away from their biological parents, such as institutions, foster homes, child-headed households or living with extended family members. This can be due to the bereavement of parents; abandonment; mental health or drug use making the parent feel unable to care for the child; abuse meaning the home is not safe; or the issue of poverty.

All children become additionally vulnerable due to the loss of parental care. It is understood that a critical feature of a child's social and emotional development is the opportunity to form attachments with a significant caregiver who is warm, sensitive and responsive. There is much psychological research on the impact of severed or absent relationships of attachment for children (see Appendix Two: Further Reading).

An HIV diagnosis in childhood can have a negative impact on a child's sense of self-esteem and self-worth. It can challenge a child's sense of hope about their future, their life, and relationship opportunities.

Work with C&ALHIV who are growing up away from their biological parents, and particularly those who are living in institutions for whom a significant attachment relationship is more problematic due to the group care environment, will require special attention. They may face the emotional vulnerability and psychological impact of growing up without a secure attachment relationship with a parent, and the impact of a stigmatised illness which they may have limited understanding of. It is

important to understand the difficulties they could face in forming trusting and secure relationships with those caring for them, and acknowledge this in working practice.

Approaches to one-to-one support and group work should consider activities to build self-esteem, help C&ALHIV to feel empowered and create a sense of hope for the future. Consideration also needs to be given to how to integrate C&ALHIV with their HIV positive peers who do live with their biological parents and consider ways to challenge any negative attitudes within the peer group (if this should occur), stressing the profound shared experience of growing up with HIV.







## 2.2 Managing HIV during adolescence

### Isolation

Many ALHIV describe the impact of HIV making them feeling isolated and different. Even in high prevalence settings, the stigma that surrounds HIV and the lack of people living openly means that ALHIV can feel like they are the 'only one'. This sense of isolation and feeling alone in managing HIV can impact profoundly on psychological and emotional well-being. This is why it is so important to have open conversations about HIV with CLHIV at a young age – normalising HIV before societal views can influence the child – and to continue these conversations and link them with their HIV positive peers as soon as possible.

In low prevalence contexts, some C&ALHIV will be geographically isolated, which can present challenges to accessing their HIV positive peers. Direct outreach work and using residential

interventions has been shown to be successful in overcoming this (see Section Five: Residential Interventions). Linking adolescents through online communication and social media is an option, but face-to-face contact is by far the most successful model. There may be financial barriers such as travel or accommodation costs to overcome and preliminary work may need to be undertaken with parent/carers or children if there is initial resistance or fear, but the impact of peer contact on ALHIV can be life changing. The authors of this handbook have worked with many geographically isolated ALHIV and their feedback following contact with their peers demonstrates immense relief in feeling that they are not alone, building emotional resilience and reducing self-stigma.

### Stigma and self-stigma

*Watch video: Self-stigma - <http://vimeo.com/112427513> (password: chiva)*

Stigma devalues people and generates shame. It blames and punishes certain people or groups to detract from the fact that everyone is at risk. Stigma focuses on existing prejudices and further marginalises people. The stigma attached to HIV comes from it being associated with sex, disease and death, and with illegal or culturally taboo practices.

The real and perceived stigma of having HIV can lead to feelings of isolation and difference and experiences of discrimination and abuse. Stigma is also

harmful to individuals because it can lead to feelings of guilt or shame. In this way, stigma can become internalised and lead to what is referred to as 'self-stigma', where the individual has negative beliefs about HIV and therefore negative beliefs about themselves. Self-stigma can result in denial of HIV, non-adherence, and refusal to talk about HIV. Research carried out into self-stigma states:



*'It leads to fear of disclosure, which leads to social isolation, a life of no sex or anonymous sex that avoids disclosure, negative body image, feelings of hopelessness' [10].*

Many factors can influence the development of self-stigma: the views of the community a person lives in; how and when they were told they have HIV; and their experiences of HIV (such as abandonment or bereavement). For practitioners to understand the self-stigma of ALHIV it is important to

understand the holistic experiences of the child.

Working to reduce self-stigma is ultimately going to require a person changing their self-beliefs. Activities and discussion that support ALHIV to explore their self-perception, future aspirations and how they define their identity in relation to HIV, will start to work towards this change. Professionals should take a questioning approach to those beliefs that are self-stigmatising, in an effort to challenge and change them.

### Taking medicines

Watch video: Adherence - <http://vimeo.com/112425742> (password: chiva)

The development and advancement of ART means that HIV is now defined as a chronic manageable health condition. However, ART must be taken regularly and if doses are missed, the virus can mutate and the medicines no longer

work. Although there is a number of different ART available (and this will vary in different settings) there are a limited number of combinations and poor adherence can lead to multi-drug resistance, morbidity and mortality.



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Adherence can be a complex psychological issue and solutions can be challenging. Ensuring that C&ALHIV

have a good understanding about HIV, how medications help to control it and a proper understanding of what side-

effects are and how they might manifest on different regimes, will support adherence. For C&ALHIV, adherence is a family/home issue and where possible, adherence support should be given to the family when the child is young, developing good models of adherence from an early age.

As Dr Caroline Foster sets out in Section One, poor adherence is not unique to HIV

### Approach one: Practical support

C&ALHIV and their parent/carers may need practical tools to support them in remembering to take their medicine. This can be simple charts, pillboxes,

and adherence patterns are developed in childhood. To that end, it is important to work with a family around adherence as soon as possible in an attempt to set up good models when a child is young.

In its simplest form, adherence support can be divided into two necessary approaches:

alarms, mobile phone apps, etc. These techniques help those who struggle to establish daily routines with medication.

### Approach two: Psychological and emotional support

The more complex area involves ALHIV who still feel unable to take medicine despite knowing all the facts about how important this is. This is not uncommon and it is important to understand how

and why this situation occurs, as well as seeking to develop ways to work with the adolescent to explore how they can manage this.

There are multiple reasons why ALHIV do not take their medication, including:

- Feeling they have some control
- That the medication is a daily reminder that they have HIV
- They feel well and the side effects make them feel unwell
- They feel that they do not have a future, and see no point in taking medicine
- Wanting to feel 'normal' and be the same as their HIV negative peers.



HIV is highly stigmatised and understanding self-stigma is significant to an understanding of poor adherence. Reflecting on ALHIV's early childhood experiences of HIV, attitudes to medication in their home and their experiences in healthcare will support practitioners understanding and ALHIV

to see these links. It may be that there are other significant events or experiences not connected with HIV that impact on adherence, such as experiences of abuse, abandonment, parental drug-use, adolescents using drugs, caring responsibilities, issues at school and within friendship circles.

One-to-one and group work will offer the opportunity to explore these wider experiences. It is important to approach the adolescent holistically, to show an interest in them as a person and not simply in their HIV. Studies in the UK have shown that Motivational Interviewing has had some success in addressing adolescents with extremely poor adherence. [11] If an ALHIV is not taking medication and no intervention at that time seems to be working, focus should be on positive risk management, which means accepting the ALHIV is not taking

their medication and supporting them to prevent onward transmission through safer sex or injecting practices during this time. Above all else, it is important that the ALHIV is not judged for their decisions relating to medication, that their choices are accepted and they are kept engaged within healthcare.

Appendix One offers group activities around knowledge of HIV, medication and exploring self-stigma and self-esteem.

## Sex, sexuality and sexual health

*Watch video: Sex and sexual health - <http://vimeo.com/112431684> (password: chiva)*

Being born with a highly stigmatised, sexually transmitted infection can have a significant impact on ALHIVs' views on sex. As sex is a key route of HIV transmission, it is critical that ALHIV have good quality sex education from an early age.

Many people find talking about sex embarrassing or uncomfortable but it is very important that ALHIV have the opportunity to understand more about sex and explore their concerns or worries. As with all difficult conversations, the earlier they are started, the easier they are to have and they establish a relationship centred around openness and trust. If a worker feels uncomfortable talking about sex, they should locate a member of staff or expert who can undertake this work.

It is helpful to begin conversations with young children earlier as this helps to establish trust and demystifies the topic of sex. When talking to CLHIV

about sex, young children benefit from conversations that relate to biology, so they start with an understanding of human reproduction and are used to the correct terminology. When discussing sexual relationships, these can be contextualised in adulthood and love, so the younger child feels safe and not concerned.

With ALHIV, conversations and workshops should focus on negotiating the sex that they want and safer sex practices (see Appendix One for activities to explore this). These can present many challenges to the cultural and religious belief systems of individuals and communities. It is essential that these beliefs do not interrupt or influence the work that is needed to equip ALHIV with knowledge and understanding about sex, explore their feelings about their sexual identity, and consider what they want from their relationships. This is child-centred practice where the needs and rights of

the child are central to the work. Many ALHIV may feel they are 'not allowed' to have sex, reflecting societal stigma. Open

conversations with practitioners will and should challenge this.



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Work with adolescents about sex in the context of their relationships also involves exploring issues of empowerment. Globally, young women are at greatest risk of HIV infection, and this is understood as being due to gender inequalities and the challenges faced by women in securing condom use. Negotiating condom use can be challenging for adolescents and exploring this with them first, will help. It is important that they are able to use condoms correctly and have the opportunity to experiment with this and ask questions. It is also important to provide ALHIV with the space to explore scenarios and develop awareness and

understanding of how to negotiate condom use.

Sexual interaction does not always go as planned and as such it is important to talk about what happens if no condom is used or a condom splits, including emergency contraception and post-exposure prophylaxis (where available). All this should be undertaken in a non-judgemental way, allowing for honest responses and discussion. This will lead to conversations about when you tell a partner you are HIV positive, which is possibly one of the most challenging areas for ALHIV and is covered below.



## Talking to others about HIV

Watch video: Talking to others about HIV - <http://vimeo.com/112542022> (password: chiva)

The World Health Organization guideline strongly encourages working to strengthen support for disclosure by adolescents, stating that:

*'Disclosure is viewed as a critical component of successful adherence as it opens up an environment of trust and support' [12]*

Anyone living with HIV may need support in deciding who they want to share their diagnosis with and how they will do this, as it can require skills and confidence.

Adolescence is a period of child development where friends become greatly significant. Many ALHIV say they would like to share their HIV status with a friend, but are afraid to. Concealing HIV can bring stress and anxiety leading to the adolescent creating distance between themselves and their peers and avoiding circumstances that might make concealing their HIV status more difficult, such as overnight stays.



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This issue becomes more apparent when ALHIV begin sexual relationships, especially in those countries where transmitting HIV can lead to a criminal prosecution. When C&ALHIV are told their diagnosis, especially those who have lived all their life with HIV, it is likely they will be told not to tell anyone else, yet there should come a time when they

want to share this information. When the other person's response is supportive, this is a hugely important experience in helping to build the capacity to accept life with HIV. Therefore, it is essential that work with C&ALHIV addresses the issue of sharing HIV with other people and that this is a recurring theme in the ongoing work with this group.

Building communication skills, confidence and developing resilience will all prepare ALHIV for telling others about their HIV. This work should cover:

- Considering who it would be helpful for them to tell and who they may choose not to tell.
- When and in what situations they would want to tell.
- What might help them to prepare for telling someone, such as starting up abstract conversations about HIV to see the person's response
- What would be the consequences of a negative response and how they would manage that.



It is important to present the equal possibilities of a positive and negative response, and consider what would help a positive response to be achieved. Do not dissuade ALHIV from telling others, even whilst helping to prepare them for the possibility of a negative response.

This can compound the feelings of self-stigma and HIV being something 'wrong'. ALHIV should feel they 'own' their HIV; this is their health condition and they should be empowered to make the decisions about who in their life knows about it.

### Having no home

Children and adolescents whose well-being is of particular concern are those who have no home and either live on the streets or stay with others in unstable conditions. This group is highly vulnerable to sexual exploitation, drug use and poor health and their life-style and living conditions present particular challenges to providing support around the self-management of HIV.

Emphasis should be on the holistic needs of the child or adolescent. A person who is hungry and without shelter is not in a position to come to terms with living with HIV or to manage their health needs without first having these basic needs met (see Appendix Three). It is important

to be willing and able to understand this and focus support on meeting these basic needs and developing the child's capacity for self-care. Supporting these children will require flexibility and expectations based on very small steps, focusing clearly on immediate and basic needs.

Professionals will need to be mindful of the anxiety they may experience when an ALHIV on the streets is not accessing health care or accepting their diagnosis. All work has to be child-centred, focusing on the point at which the child has reached with their HIV, rather than where the worker would like the child to be.



## 2.3 HIV and the family context

### How HIV was acquired

The way a child or adolescent was infected with HIV can affect their response to the virus. For example, where the child is vertically infected (from their mother) and the mother has then died, this will have a huge impact on that child's view of HIV. If the mother is still alive, there may still be issues within the family, such as the mother's guilt or inability to talk openly about HIV. It is quite likely there will be HIV affected siblings who are unaware of HIV in their family and so the

home is not an open and accepting place to be HIV positive.

If a child was infected through sexual abuse, rape or sexual exploitation, HIV will be intertwined with the emotional trauma of that experience. If an adolescent acquires HIV through consensual sex or drug use, this can provoke the ALHIV to feel personal blame due to 'their behaviour.'



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Be mindful of the potential for different responses to children who were born with HIV and those who acquired it during adolescence. Where appropriate, it may be necessary to challenge perceptions of blame from others or self-blame. Often

children born with HIV can be seen as the 'innocents' of the epidemic, whereas those who acquire it through consensual behaviour are somehow not. This stems from a moral response to HIV and fuels stigma.

### Parents, carers and siblings

Children should be viewed in the context of the family, and where a C&ALHIV is living in a family, professionals supporting

that child need to develop an ongoing relationship with the parent/carers. As the child develops into an adolescent, it

is important to encourage the adolescent to take more control over their health and that they have the opportunity to be seen alone, whilst still maintaining this relationship with the parent/carer.

Within an organisation it is important to have a clearly understood approach to working with the families of the C&ALHIV. This will include:



- The legal requirements, such as the consent for children or adolescents to access the service, and at what age adolescents are able to self-refer without parental consent.
- The professional duties to report concerns about child welfare, which could involve concerns about child abuse, where these concerns are not shared with the parent if they were thought to be the cause of harm.

Aiming to establish a child-centred ethos requires an organisation to place the child's best interests at the centre of their work, whilst forming relationships with parent/carers. This may involve some potential tension with parent/carers, commonly around the sharing of information about HIV with children.

Parental resistance to tell a child their HIV status is typically due to fears and anxiety about whether the child will cope with the information, or whether they would then tell other people. It is important that professionals feel able to advocate for C&ALHIV. This may require them advocating for the child's best interests and possibly some mediation work with parent/carers to ensure the child's needs and rights are met.

HIV is frequently a 'family illness' and this can lead to the mirroring of HIV coping behaviours, where children adopt similar approaches to HIV as their parents, with poor adherence being an example of this. Where there is helpful modelling from a parent, who adheres well to their medication and is able to have open conversations about HIV with a child, this is clearly supportive. However, when the opposite is true, professionals may need

to undertake some wider family work.

It is likely that a C&ALHIV will be living with HIV negative and positive siblings. This can impact on open and honest conversations in the home as commonly, an HIV negative child is not told there is HIV in their family, even though they may have worked this out themselves [13]. This means that the home is a place where HIV is maintained as a secret, which can contribute to the person/people with HIV in the household feeling stigmatised, as difference is reinforced through secrecy around HIV.

It is critical to appreciate how HIV is responded to in the home environment. This will help to identify the support needs of C&ALHIV, particularly around their opportunities for open conversations about HIV. Parent groups can be useful to enable parents to come together to share the specific experience of parenting a child who has HIV. Emphasising the benefits of sharing experiences, reducing anxiety and using workshops and courses to equip the parent/carer with the skills to talk openly to all their children about HIV, will benefit the entire family (see Appendix Two: Further Reading).

## Caring responsibilities for parents and/or siblings

When growing up in families where members have a chronic physical or mental health condition, or are misusing drugs or alcohol, it is common for children to take on additional responsibilities in the home. In high HIV prevalence areas, this includes child-headed households where older children take on the parenting role of their younger siblings. The responsibilities of the child in all settings will vary both between individual circumstances and social/cultural norms and expectations. It is when these responsibilities extend beyond the norm that they can have significant impacts on a child's happiness, interaction with their peers, ability to form friendships, educational achievements and their health [14].

Responsibilities can extend far beyond housework, and may include direct caring roles for siblings and parent/carers. Children can take on additional emotional worry and anxiety about their family members, particularly in relation to their health. They may have concerns

about the financial or housing situation for the family, and where the parent/carer is experiencing profound mental or physical ill health or addiction issues, they may be running the family home from a young age.

C&ALHIV have a family experience of HIV. If open and honest conversations about family HIV do not take place, C&ALHIV may not be fully aware of their own or their parent/siblings HIV status whilst caring for them. This will then present additional stress, fear and anxiety.

When supporting C&ALHIV, ensure this aspect of their life is assessed on an ongoing basis, as the proportion of responsibility and its impact will vary over time. It is known that children who are carers have benefitted from support that offers them some time away from being a carer, contact with other children who share and understand this experience, and being given the opportunity to talk about any concerns and anxieties.

## Family drug use

Where injecting drug users are over-represented in the demographic of HIV positive people, many C&ALHIV will be living in homes where there has previously been, or is currently, drug use. In most cultures, drug use is not seen as acceptable behaviour and injecting drug users face stigma and negative stereotyping. When working with families where there is current or previous drug use, or where a child has been orphaned or abandoned by a drug-using parent, non-judgemental approaches are essential (see Section

Four: Communication for more detail).

It is common that people turn to misusing drugs or alcohol in adulthood due to childhood trauma such as abuse or neglect. Drug or alcohol use may have become a coping mechanism for dealing with this and therefore these are vulnerable adults. Children living in this context will share similar experiences to those with caring responsibilities, with this impacting on their health, happiness, education, friendships and development.

All C&ALHIV need to feel they and their

family are not judged and that the service provided, whether in health or social care, is a safe place to talk openly about their life. Within group work for C&ALHIV, all must be treated the same, whether they live with a drug-using parent, they have spent time in an institution or have any other issues that have brought additional adversity to their life. Growing up with

HIV can be a profound and unique experience that brings adolescents from very different backgrounds together and using this as a focal point can overcome the many differences within the group.

### SECTION THREE: VULNERABLE ADOLESCENTS WITH BEHAVIOURALLY ACQUIRED HIV

There are a group of adolescents that become infected with HIV during childhood. For most, this will be through unprotected sex, sharing injecting equipment and in some parts of the world, hospital based transmission. This section focuses on the particular groups of adolescents that acquire HIV that are seen as harder to reach: those living on the streets; those misusing drugs and alcohol; those who have experienced sexual exploitation or are engaged in

transactional sex and adolescent men who have sex with men.

These groups can be extremely isolated and vulnerable. This isolation may be a primary factor in the adolescent having acquiring HIV, and will present practitioners with potentially complex psychological and social issues that will need to be addressed, before supporting the adolescent to manage their HIV.



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An open, non-judgmental approach will be critical for engaging and retaining these groups of adolescents. Staff need to be available and accessible to ensure the

adolescents receive accepting responses to the needs they present with.



This section will explore key issues for the following groups:

### **3.1 Insecurely housed or living on the streets**

### **3.2 Sexually exploited ALHIV and involved in transactional sex**

### **3.3 ALHIV who misuse drug and/or alcohol**

### **3.4 Adolescent men who have sex with men (AMSM)**

### **3.5 Engaging with health and managing HIV**

### **3.6 Ensuring inclusion of hard-to-reach groups**

Most issues are not exclusive to one group and are often interconnected and key themes will occur throughout.

## **3.1 Insecurely housed or living on the streets**

This is likely to be a common issue for many ALHIV who acquired HIV behaviourally. They may have had to leave their family home due to their sexual orientation; to escape abuse; were forced to leave, or grew up in an institution and have no family. Having no housing, or being insecurely housed, will make any adolescents extremely vulnerable. For this particular group the addition of needing to manage their HIV and health become extremely challenging

When a person does not have their basic needs met – food, shelter, safety, warmth – all their other needs become inaccessible to them. The needs of ALHIV living on the streets or insecurely housed will begin with the basic needs for shelter and food. They may resort to crime and transactional sex to acquire money or gain access to shelter or food

(see Appendix Three: Maslow's Hierarchy of Need).

Work with this group will need to begin with a holistic needs assessment that recognises their priorities, addressing these basic and fundamental needs first (see Appendix Five: Needs Assessment Form).

Provision of basic needs can also be a means to engage this harder to reach group. Providing a hot meal, drinks and somewhere safe to be (to wash, change clothes etc), ideally safe over night accommodation, but if not, at least during the day, demonstrates care and concern and can enable a relationship of trust to be built.

## Issues to consider when supporting this group:

### Mental health

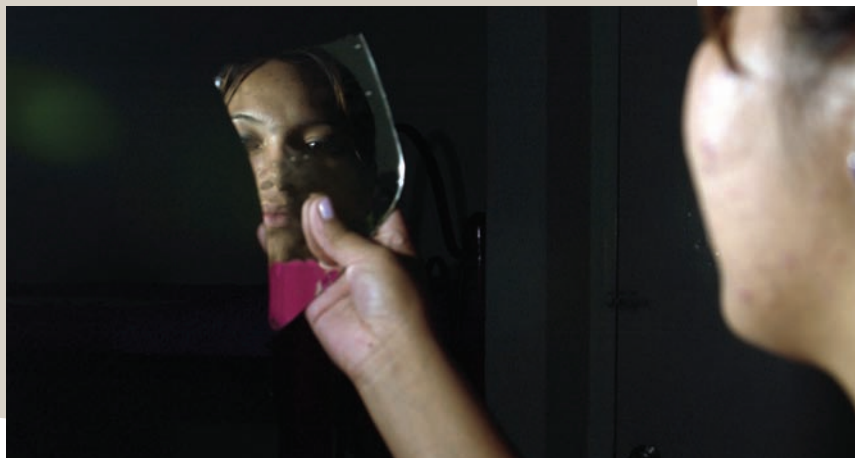
Depression and anxiety are likely to be significant and a sense of hopelessness and fear for the future can dominate. If during childhood the adolescent did not experience a caring relationship with an adult they were able to form a secure attachment to, there are likely to be far

reaching psychological impacts. Suicidal thoughts and attempts are also likely, with the long-term impact of unmet emotional and physical needs. There is a high risk of exploitation of the ALHIV. As such services can present a critical lifeline for this group.

### Sexual exploitation and abuse

Where an ALHIV has no secure accommodation or access to money, they are highly vulnerable to sexual exploitation and transactional sex. This is covered in more detail in the next

section, but it is important to remember that if the ALHIV has no-where to live and no access to food, they will be compelled to find the means to survive regardless of the harm it presents to them.



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### 3.2 ALHIV involved in sexual exploitation and transactional sex

Where an adolescent is coerced into exchanging sex for money, this is sexual exploitation. If an adolescent is offered drugs, housing, food or 'gifts' in return for sex, within this section this is referred to as transactional sex. Both may be portrayed as a 'relationship', for example

an older man 'dating' an adolescent, whilst providing money for them to take to her family, or providing them with drugs. But practitioners should explore this 'relationship' with the ALHIV to ensure there is no coercion or violence.

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If the ALHIV is a minor, sexual exploitation and transactional sex are child protection concerns and they should be viewed

from this perspective rather than as sex work.

### Issues to consider when supporting this group: Meeting basic needs

If transactional sex is the way the ALHIV meets their basic needs for shelter and food, then engaging the ALHIV to explore other options and considering the possibility for service support in this area will be key.

It is important that staff remain non-judgmental, and work on building trusting relationships. This work should

focus on supporting the ALHIV to see they have value, worth and a future to look forward to, helping them to explore broader aspects of themselves and their skills and abilities. It may be useful to explore theories of behavioural change (see Appendix Four: Motivational Interviewing information)

### Mental health

There can be significant mental health impacts from experiencing sexual exploitation and transactional sex. The emotional difficulties related to childhood sexual abuse is known to be linked to drug and/or alcohol misuse in adolescents and adulthood (research can be found on this in many different countries).

Opportunities for emotional and therapeutic support will be important to establish a clearer understanding of how the ALHIV's life experiences and behaviour are linked. This will help them to build the capacity to start to make changes and reduce risks of further harm.

### 3.3 ALHIV who misuse drug and/or alcohol

Adolescence is the transition between childhood and adulthood and is a time of experimentation, so some alcohol and drug use is relatively common. However, misuse of drugs and alcohol in childhood often stems from a need to escape current or previous experiences of abuse (physical, sexual and neglect). It can also be a way to cope with current life situations, such as leaving an orphanage or having to live on the streets. Some ALHIV will have grown up in household where drug and/or alcohol misuse occurred, and as such, it is familiar and 'normal' behaviour to them.

Drug and/or alcohol misuse can lead to engagement in other criminal activities, such as transactional sex or theft, to acquire money to buy the drink or drugs. When taking drugs or excessively drinking, the adolescent may behave in a way which is culturally unacceptable, violent or offensive to others. They will also be particularly vulnerable to sexual exploitation.

The numbers of ALHIV who misuse drugs and alcohol will vary from country to country. Working with this group will be challenging and complex, and workers



will need further information and training. Theories, such as Motivational Interviewing, have been specifically designed to work with addiction and support behavioural change. These can be extremely useful tools in

understanding why someone is behaving in a certain way, and how to support them in changing this (see Appendix Four: Motivational Interviewing).

### **Issues to consider when supporting this group: The law**

Each country will have different laws relating to the consumption of alcohol and the use of recreational drugs. It is important that the practitioner is fully aware of what the law in their country expects from them.

An organisation will need a clear policy on drug and alcohol use on their premises. This will be determined by the legal

context, but there are some possibilities for continuing to engage with ALHIV who have been drinking excessively or are under the influence of drugs. It may be possible to designate a specific space where those under the influence of drink or drugs can go if they arrive at the service, in order that they can be safe, and that they are not disruptive to others.

### **Meeting basic needs**

If an ALHIV who misuses drugs and/or alcohol does not have their basic needs met, they are likely to be stuck in a cycle where they take drugs and/or alcohol to escape their current life situation, and in doing so, perpetuate their circumstances. Such issues are likely to dominate the

ALHIV's life and it will be difficult to engage the adolescent in work around managing their HIV whilst they remain in a chaotic cycle of substance misuse. So the priority will need to be addressing this.

### **Mental health**

A lack of emotional and practical support, rejection, isolation and prejudice can lead to additional risks for this group of adolescents. They are often completely disengaged from social institutions, unlikely to access health and have high suicide rates. They are at greater risks of harm relating to sex and will experience high levels of sexual exploitation/transactional sex.

As mentioned above, most adolescents misusing drugs and/or alcohol are often doing so to escape childhood trauma, and their need for emotional support will be extremely high. Staff will need to remember that the ALHIV's behaviour is a reflection of poor mental health due to childhood trauma. This will enable the ALHIV's mental health needs to be explored and allow a better understanding of their current behaviour.

### **Sexual exploitation and abuse**

This group are likely to be involved in transactional sex or be sexually exploited

and the impacts of this and the issues it raises are set out in 3.2.



### 3.4 Adolescent men who have sex with men (AMSM)

In many societies, being physically attracted to the same sex and physically expressing this attraction is viewed as immoral, and in some countries, illegal. The term MSM is used because not all men who choose to have sex with other men would consider themselves to be homosexual or 'gay'. MSM will be present in every country and community, and can face extreme prejudice, isolation and the threat of violence. MSM are over represented in the HIV infected

community, being 19% more likely to be living with HIV (UNAIDS, 2014) [15]. This, coupled with the experience of social prejudice, can mean that AMSM living with HIV may not have access to good quality sexual health information, healthcare and support. Also, a percentage of children born with HIV will be MSM, lesbian, bisexual or transgender, which can present them all with dual prejudice complicating further their experience of growing up with HIV.

#### Issues to consider when supporting this group: Meeting basic needs

As stated above, AMSM may have either been forced to, or felt unable to, remain in their family home. They could be insecurely housed or living on the streets

and experience all the vulnerabilities this presents as set out in 3.1. As with anyone in this situation, these issues will need to be addressed first.

#### Mental health

Lack of social support, rejection, isolation and prejudice due to sexual orientation, can lead to additional risk factors in AMSM. Multiple research shows they have increased risk of poor health outcomes, suicide attempts, misuse of drugs and/or alcohol, and more risk taking relating to sex. These responses and actions

are not unique to AMSM, other ALHIV may also face these challenges, but this group are particularly vulnerable due to the isolation and rejection they may experience. Awareness, knowledge, understanding and empathy are all essential in engaging and supporting AMSM.

#### Sexual exploitation and abuse

Where a society, community or family either ostracises or criminalises sexual orientation, this can lead to AMSM becoming more vulnerable to abuse and sexual exploitation. When assessing an AMSM, it is important to explore

whether the 'relationships' he is having are abusive, exploitative or of financial necessity. Open questions and neutral language are important to enable him to feel safe and accepted.

### 3.5 Engaging with health and managing HIV

All these groups of ALHIV may have experienced discrimination in the health

sector and not be willing to engage with services. Where there are legal issues

(for example if homosexuality or drug use are illegal), this could add further complications to accessing healthcare provision. Support will be critical to help the ALHIV access the services and help they need.

Without an address, in many countries, it can be difficult and sometimes impossible to access health care provision. Where some form of payment needs to be made either to access a doctor or purchase medication, this will be a low priority for

the adolescent who barely has enough money to feed himself.

Where an ALHIV is misusing drugs and/or alcohol they are unlikely to be engaged with health services. This group are at imminent risk of morbidity or mortality, as they have a compromised immune system and are misusing toxic substances. They are at risk of significant harm, as well as onwardly transmitting HIV through sharing injecting equipment or unprotected sex.



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To engage an ALHIV it is critical to build a trusting relationship with them. A named doctor who may work well with these groups and be willing to come and visit them at your service or on the streets will help this. A support worker may be needed to assist an adolescent to engage with healthcare.

Where available, outreach health services and flexible clinic open times are especially important. Clinical staff need to be non-judgmental and able to

offer a range of services. Harm reduction approaches have an important role in work with these groups and opportunities to either access these or develop them should be found. Access to sterile syringes, free condoms, sexual health screenings, sexual health education and support with negotiating safer sex, are all examples of harm reduction approaches. These strategies are designed to reduce the harmful associated consequences of the adolescent's current behaviour.

If there are opportunities for vulnerable, insecurely housed adolescents to have some basic needs addressed alongside

health care provision, this is likely to encourage successful engagement and retention.

### 3.6 Ensuring inclusion of harder-to-reach groups

There are many shared experiences amongst these groups of harder-to-reach adolescents who have behaviourally

acquired HIV. Key areas to consider in service development are:



1. Flexible access to services and availability of staff at different times of day and over the weekend.
2. That services make their acceptance of all ALHIV, however they acquired HIV, explicit and publically known.
3. A non-judgmental approach is expected from all staff and service users.
4. Where possible, basic needs are available such as food and drinks, access to clothes washing facilities and a place to wash/shower.
5. To work collaboratively with healthcare providers to support these ALHIV to engage in healthcare.

With strong policies and clear carefully planned practice, the harder-to-reach ALHIV should be engaged with their peers who have grown up with HIV. The shared experience of living with HIV can be used to generate an acceptance of each other and have positive peer support affects.

The past experiences and behaviour of the ALHIV are confidential and should not define them for the rest of their life. If they are joining a group, how they acquired HIV is unimportant and does not need to be shared, unless the ALHIV wishes to do so.

Inclusion and acceptance needs to be encouraged in services users, and any discriminatory language or behaviour must be challenged. It is important this is done calmly but immediately, so

everyone can see this is unacceptable. Explaining how what was said or done made others feel and draw the parallel of how the service user would feel if such things were said or done to them just because they have HIV.

Ensure adequate support is in place so these vulnerable ALHIV are not set up to fail. Set small achievable goals, have key staff available who the ALHIV knows and trusts and ensure they are aware that the door to your service is always open to them, whatever happens. Their life maybe chaotic, but knowing the service is there will mean they know where to go in times of need, crisis or if they decide they want to try to change their life.

## SECTION FOUR: APPROACHES TO PRACTICE AND POLICIES

This section covers approaches to specific practice areas. It outlines what has been learned through practice experience and research. Its ethos is based on the United Nations Convention on the Rights

of the Child (1989), which internationally established children's rights and a focus on children's best interests as central to practice.



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Section Four includes policy considerations for each practice area.

There are additional policy examples in Appendix Five that support this section.

### This section covers the following areas:

- 4.1 Communication**
- 4.2 Talking to children about their HIV**
- 4.3 Confidentiality**
- 4.4 Safeguarding children and child protection**
- 4.5 Managing behaviour**
- 4.6 Ensuring inclusion and equality**
- 4.7 One-to-one work**
- 4.8 Group work**
- 4.9 General practice points**



## 4.1 Communication

*Watch video: Communication - <http://vimeo.com/112425744> (password: chiva)*

The approach taken to communicating with C&ALHIV is critical in achieving their successful engagement in a service. Constructive and positive communication should be at the heart of a support service. It is important that workers' personal beliefs do not influence their engagement with C&ALHIV and their family. It is important to ensure people accessing support feel respected and not judged, regardless of their life

circumstances. There has been much written on theories of communication and how to work with people to support behavioural change.

In the UK, Motivational Interviewing has been seen as a successful model that offers core principles for communication. Elements of communication reflected in the Motivational Interviewing technique are:

### Reflective listening

This involves actively listening to the person and summarising back what they have said to show they have been heard. Reflective listening builds trust with the

individual, making them feel valued and understood, and supports them to process their feelings.

### Affirming the person's freedom of choice and self-direction

Children, adolescents and adults all need to feel that they have control over their lives. When supporting someone to change their behaviour, such as in adherence work, they need to believe they have choices. They choose what

they do and how they do it. This is empowering for the individual and also demonstrates that their decisions are respected, whether the worker agrees with them or not.

### Being non-judgemental

A worker's own beliefs should not influence their responses and interactions, and it is important to guard against this. Even when conversations are

ethically or morally challenging, the role of the worker is to listen to the person and support them, not to lecture or tell the adolescent that they are wrong.

### Expressing Acceptance

Often, stigmatised and marginalised people do not feel accepted and included. Ensuring inclusion and

showing acceptance and respect will support their engagement, build trust and improve self-esteem.



## Language

As a practitioner, it is important to be aware of the language used so as not to alienate people with complicated or technical terms. Also, ensure that the

language used is not discriminatory or could be unwelcome by particular groups.

### How adolescents have said they want to be communicated with

**Listen:** carefully and without trivialising or being dismissive of the issues raised

**Be available and accessible:** be able to offer regular and predictable contact

**Be non-judgemental and non-directive:** accepting, explaining and suggesting options or choices

**Have a sense of humour:** it helps to build a rapport

**Straight talking:** with realism and reliability; no false promises

**Be trusted:** maintain confidentiality with children and consult with them before taking matters to other people



*Children Speak: children, trauma and social work [16]*

## Policy considerations

Communication should be a theme in a range of policies and practice guidance. For example, an anti-discrimination or equality and inclusion policy that outlines how all groups of people should

have equal access to a service to seek support, should include a requirement to ensure positive and non-judgemental communication for all people accessing the service.

## 4.2 Talking to children about their HIV diagnosis

*Watch video: Naming HIV - <https://vimeo.com/112460124> (password: chiva)*

All children with health conditions need to understand their own health needs as they grow up. For children who have had HIV from birth, it is now an agreed consensus [17] that they will be told about the virus they live with from an early age. This should be planned, with support of their knowledge and understanding as an ongoing process and not a one-off event.

Children do not cope well when they are lied to, particularly by people who are in positions of trust, such as their parent/carer, doctors and health workers. Practitioners have described how ALHIV report feeling anger and resentment when realising they were being lied to about their HIV.



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In order for children to live well with HIV, to attend their clinic appointments independently later in life and to adhere to their HIV medication, they need to have established strong relationships of

trust with those who are responsible for their care. The child needs to be an active participant in this relationship, feeling that they have a say in decision making and feeling that they have some control.

### Managing fears

Children who visit hospitals from a young age and take treatments to manage their HIV will soon realise differences between themselves and their HIV negative peers. Children's capacity for understanding health and ill health has been found to be well developed in most children between the ages of 6 and 8 [17]. Children who do not receive clear information about what is wrong with them will create their own ideas about this, which can be a source of significant fear and confusion.

There can be a lot of fear and anxiety in families where a child does not know they have HIV. This can lead to stress and difficulties in the relationship between parent/carer and child, with the parent/

carer worrying about their child finding out, about the time when they must tell the child, and the child becoming increasingly aware that something important is being kept from them.

WHO's (2011) guideline on telling a child their HIV diagnosis points to research that indicates concealing HIV status may lead to or exacerbate depression, worry and other negative mental health outcomes for families. This can potentially interfere with treatment and affect family life, including parenting ability and the child's social and academic life [18].



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## Normalising HIV

It is now common practice with other chronic illnesses, to tell the child about their health condition at a young age. This has been found to effectively support the child's understanding of their health condition as they grow up, and support their psychological and social adjustment to living with a chronic health problem. Even where the health condition is terminal, it is still considered best practice for the child to be told what is wrong with them and to enable them to participate in decisions that are made about their health care and treatment.

Treating HIV as being different to other chronic conditions supports HIV related stigma. It forces people who live with HIV to do so in secret, and creates a context where telling children about their HIV is something many parent/carers are fearful of. It can lead to professionals 'mirroring' the societal stigma around HIV, as the professional colludes with

secrecy rather than treating HIV as any other health condition is treated. HIV becomes something that is difficult to talk about openly in families, institutions and in professional settings where children attend. This can lead to children not being supported in talking through their feelings, which is understood as an important coping mechanism for dealing with adversities, problems and managing long-term health conditions.

It is key for professionals to consider how they can play a part in normalising responses to HIV, in order that HIV is not treated so differently from other chronic health conditions, thereby helping to reduce the stigma associated with it.

There is an important opportunity with young children to support their understanding of HIV from a young age, which will enable them to grow up and live well with HIV and reduce self-stigma.

Young children will not yet have a wider understanding of HIV as something that is feared.

In order for professionals to feel confident about presenting HIV in this way and be active in reducing HIV stigma, it is important that they have the opportunity to reflect upon their own knowledge and understanding of it. They need to consider how and where they have open and honest conversations with C&ALHIV and their families about HIV, and how

comfortable and competent they feel in doing this.

As stated in the Introduction, under the UNCRC, children have the right to information about their health. If a child does not receive information about their health condition and they are considered to have the capacity to understand this information, the above rights could be seen as being violated.

## Policy considerations

To ensure consistent practice for those working with C&ALHIV, it is helpful to have an organisation policy about children's knowledge of HIV. This should include:

**a) An age band that stipulates when it is expected children will be told about their HIV status.**

The WHO guideline suggest this should be considered from the age of 6, with consideration given to the child's cognitive capacities and individual social circumstances. It is most likely that this conversation is lead by health professionals in partnership with parents, but other professionals have an important role in supporting this work and it should be seen as a collaboration, with the child at the centre. There is also an important advocacy role to be taken by wider professionals working with children to promote the child's need to be told about their HIV.

**b) A statement that reflects how professionals will respond to questions from children about their health.**

This can include stating that professionals will not lie to children and will answer

questions honestly, whilst recognising that it is not a professional's right to share information with the child without the consent of their parent/carer. This establishes a child-centred ethos.

**c) A commitment to ensuring that all staff have up-to-date training on HIV.**

This will ensure staff are confident in their knowledge and understanding of HIV. Practising talking about HIV among the staff team will create an open culture where conversations about HIV are considered normal and can be carried out confidently.

**d) A commitment to ensuring there are ongoing opportunities for children to have open conversations with professionals.**

Additionally, children will benefit from having regular opportunities for open conversations with other children who also have HIV, creating an environment of openness and acceptance around HIV. This will have a clear effect on building resilience and supporting self-esteem, leading to better coping strategies and outcomes for children who grow up with HIV.

### Policy checklist: Talking to a child about HIV

- Agreed age band for children to be told about their HIV
- Organisational response to direct questions
- Staff training
- Organisational commitment to ongoing conversations about HIV



### 4.3 Confidentiality

The stigma that surrounds HIV makes attention to confidentiality particularly important. Children and their families must be able to control who knows

about their HIV status and feel equipped to share that information as and when they want to.

#### Personal health information

HIV is personal health information and therefore, the people who this is shared with should be the decision of the HIV positive person and their consent should be sought before this is shared. This applies both to professional and personal contexts.

A child who has been considered competent enough to be told about their own HIV status should also be shown the same consideration with regards to their consent being needed to share

their HIV status with someone else. For the child who does not yet know they have HIV, consent should be sought from their parent/carer or whoever holds legal responsibility for them.

Due to the effects of HIV stigma, breaches in a person's confidentiality of their HIV status can have serious consequences. It can lead to family/relationship breakdowns and serious levels of discrimination and abuse, including being excluded from services.

#### Policy considerations

A clear organisation policy on maintaining confidentiality is necessary. This can include the following:

**a) A statement reflecting that the organisation is committed to maintaining confidentiality of people's HIV status.**

This statement should start with the organisation's commitment to confidentiality, that consent will be sought from the person before their HIV status is shared with someone else, and

that this includes children who know their HIV status. It should clearly state the circumstances where the organisation is obliged to share a person's HIV status without first seeking their consent, reflecting any national legislation that demands this.

**b) Managing the recording and storage of personal health information.**

Ensuring all records containing confidential information concerning a person's HIV status are stored securely,

minimising the possibility of anyone else being able to access this information and in line with national data protection legislation.

**c) Training for staff that ensures they fully understand the organisational requirements concerning confidentiality.**

This can include what this means for staff living in the same communities as the

families they work with and how they will manage this on a day-to-day basis.

**d) Consider including a confidentiality agreement which all staff sign to ensure a commitment to this practice.**

The agreement can reflect all the key principles outlined in the confidentiality policy.

### Policy checklist: Confidentiality

- Organisational statement on confidentiality
- Record keeping and storage
- Staff training
- Confidentiality agreement for all staff



## 4.4 Safeguarding children and child protection

Children are considered to need special attention to protect them against potential harm and to ensure their well-being is promoted. Child protection is the protection of children from risk of harm

that is non-accidental, known as child abuse. Child abuse is serious physical or emotional harm caused to children through the actions or lack of actions of an adult.

These categories help to define child abuse:

- Physical abuse
- Neglect
- Sexual abuse
- Emotional abuse.

Safeguarding children refers to all the protective actions that can be taken to ensure children are protected from harm and their well-being is promoted. When working with C&ALHIV, national legislation to protect children and the

protections given by the UNCRC must be considered in policy and practice.



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The UNCRC key principles that relate to duties to protect children are:

- All children have the right to be protected from discrimination (Article 2)
- Protection from all forms of violence, from being harmed physically or mentally (Article 19)
- Protection from work which is harmful or dangerous (Article 32)
- Protection from the use of harmful drugs (Article 33)
- Protection from sexual exploitation and abuse (Article 34)
- Protection from any activity which takes advantage of them or could harm their welfare or development (Article 36)
- Protection of child victims: children who have been neglected, abused, or exploited are entitled to receive special help to physically and psychologically recover (Article 39).

### National protection for children

At a national level, countries that have ratified the UNCRC will have these key principles enshrined in their legislation. At a local level, organisations that work with children have a responsibility to

protect the children they come into contact with from harm, and to respond to the needs of children who have been harmed.



## Policy considerations

A child protection policy helps to outline how organisations working with children will meet their legal duties and responsibilities. A child protection policy can contain:

**a) A statement on the organisation's commitment to the protection of children from harm and the promotion of their wellbeing.**

Stating that children's needs and rights are the principle concern of the organisation and establishing a child-centred ethos.

**b) The practice of staff recruitment should consider the need for the protection of children.**

Recruitment and vetting checks are an important aspect of protecting children. Ensuring professional references are sought and background checks carried out reduces the possible risks of harm by those who come into contact with children through the organisation's work.

**c) Child-centred working practice**

Consider how and where staff come into contact with C&ALHIV and the measures which are needed to ensure that this contact is as safe as possible, protecting children from potential harm. Stipulate how work with children should occur, for example, where one-to-one meetings should take place, who should be notified, or how outreach work can be

conducted to minimise risks to children and ensure the protection of staff.

This should also include the organisation's value base, where children and adolescents are treated with respect, listened to and valued.

**d) A commitment to training to ensure staff understand child abuse and child protection procedures.**

Annual child protection training is recommended in the UK.

**e) Ensure children understand what child abuse is and their right to be protected from harm.**

C&ALHIV need to know that they can talk to someone if they are worried about anything and that the organisation is committed to protecting them.

**f) Procedure for responding to disclosures of abuse from children.**

A child protection policy needs to include an outline of how the organisation will manage disclosures of abuse from children to members of staff. It will need to outline how it will respond when there are concerns raised by staff or others that a child is being, or is at risk of being, abused. This needs to be in line with national legislation and all staff must be fully aware of these procedures.

## Policy checklist: Child protection

- Organisational statement of commitment
- Safer recruiting
- Child-centred working practice
- Staff training
- Children understand their rights
- A disclosure process for reported abuse





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## 4.5 Managing behaviour

It is important to have clear expectations about the behaviour of adolescents and anyone else who accesses the organisation. These can be set out in a behaviour policy that everyone is made aware of. An important aspect of managing behaviour is ensuring that the same standards of behaviour are equally expected of children, adolescents, adults and staff. Professionals should model behaviour in their practice, demonstrating how they expect others to behave.

Clear boundaries around behaviour management help everyone to feel safe

and enable effective work with ALHIV. Positive statements about what sorts of behaviour are encouraged and expected are helpful, rather than simply outlining what behaviour is unacceptable.

The author's experience has been that where ALHIV are given the opportunity to express themselves and discuss HIV openly, they can start to exhibit some challenging behaviours, becoming upset or angry. Although these behaviours will need to be managed, it is important to acknowledge what may be causing these and provide the ALHIV the opportunity to work through them.

## Policy considerations

A behaviour policy should reflect the ethos of an organisation and be

developed with staff and children and adolescents. It can include the following:

**a) Expectations of behaviour.**

This includes how people engage with each other; what is acceptable language and ways of talking to each other, for example, outlining the need to use respectful language and being supportive towards other members of the group and being respectful to everyone including staff. It should also include how people treat the physical space, equipment and facilities.

**b) It should contain a clear outline of what is not acceptable.**

This includes abusive language from staff, other adults and adolescents, as well as name-calling, physical harm, or emotional harm caused, for example, by excluding people. It should state that the use of alcohol, illegal drugs and other substances are not permitted in the organisation.

**c) Clear and fair steps outlined in the event that any breaches of the behaviour policy occur.**

The organisation needs to decide how it will administer this, what steps will be

taken and by whom. It can be useful to have a warning system that can be scaled up, so that a child or adolescent has the opportunity to address their behaviour and is fully aware of the outcome if their behaviour does not change. Consider how to defuse conflict and ensure that responses to unacceptable behaviour remain positive and involve the child/adolescent concerned in a positive way, where at all possible.

**d) Staff training**

Staff need to feel confident and clear in their understanding of the organisation's expectations of behaviour and how to manage this, including learning techniques to defuse rather than escalate unwanted behaviour. It is important that they feel confident in applying positive behaviour management strategies to enable the expectations outlined in the policy.

**Policy checklist: Managing behaviour**

- Organisation statement on behaviour expectations for everyone
- Clear outline of behaviour that is not acceptable
- Clear steps of what will happen when policy is breached
- Staff training





## 4.6 Ensuring equality and inclusion

Due to its association with sex and other behaviours that may be considered taboo in societies, HIV remains a highly stigmatised illness. HIV stigma can mean that those who live with it feel isolated, different and of less 'worth' than others. It can lead to experiences of discrimination, abuse, social isolation and being marginalised within communities. This can further threaten people's access to services and resources.

A clear position of respect for C&ALHIV and their families in organisations

working with them can begin to address the harmful affects of HIV stigma. Non-judgemental practice from all staff is key to this. An organisation may be working with a diverse group of C&ALHIV, experiencing very different home and life situations. To work effectively, emphasis should be given to the unique shared experience of a life with HIV, bringing together peer groups of people living with HIV.

### Policy considerations

Non-judgemental practice should be at the core of an organisation or individual's work with C&ALHIV. An anti-discrimination or equality and inclusion policy should be produced to set out the organisation's stance on this. In relation to C&ALHIV it can include:

**a) A statement that ensures equality for all.**

This should outline that all C&ALHIV are entitled to receive the same quality of support and access to services and resources that are offered to others. This statement should also make clear that discrimination or abuse towards people because of their HIV status, sexuality, gender, race or ethnic origin, mental health, religion, disability, drugs or alcohol misuse or social circumstances is not accepted within the organisation.

**b) A statement on language.**

This acknowledges the power of language and sets out the expectation that language which may be offensive or is unwelcome to a particular group

of people is not accepted in the organisation.

**c) Outline what steps will be taken should any discrimination or abuse occur in the organisation.**

This should include staff and those accessing support from the organisation and set out how someone can make a complaint if they feel they have been discriminated against. This process should be simple and accessible and clearly explained to all C&ALHIV accessing the service.

**d) Staff training**

All staff should have a good knowledge and understanding of the importance of ensuring equality and protection from discrimination in their practice. They need to be committed to supporting this across the organisation and understand that this is a human rights issue.



## Policy checklist: Equality and Inclusion



- A statement on equality for all
- A statement on language
- How to make a complaint and what will happen if discrimination occurs
- Staff training

### 4.7 One-to-one work

*Watch video: One-to-one work with children and adolescents - <http://vimeo.com/112425898> (password: chiva)*

It is important to have processes established so that one-to-one work with C&ALHIV is safe and effective. Different contexts of one-to-one work

will require different planning and policy considerations, which includes information on the most appropriate staff member to carry out this work.

#### Assessment

A comprehensive assessment of needs should be carried out with the child or adolescent when they first engage with the service. This will identify needs that should be documented, and it is important to be transparent about this process with the ALHIV by

sharing it to ensure they participate. It is important to liaise with the family and any other practitioners working with the adolescent to link up support and locate any additional needs or concerns. You should ask the ALHIV permission to contact these people.



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Assessing a child's needs should be an ongoing process, thinking holistically whilst building a relationship of trust. Assessments need to be revisited to take account of changes and developments in a child's life. Building in a review process with the child or adolescent can be helpful so that previously identified needs can be evaluated and new phases of work planned.

Forms are helpful in conducting needs assessments as they provide a framework

### Peer mentors

C&ALHIV can present with complex and challenging issues and it is important to ensure that the right level of support is available for them. Using HIV positive young adults as support workers can be very powerful and hugely successful. Their presence in groups can bring inspiration and hope for younger adolescents and children. But it is important that these individuals are supervised and supported as they may have complex issues and challenges of their own.

The authors of this handbook have experienced inspirational mentors who outwardly present as coping well with their life with HIV, yet later it has

of questions and ensure areas of the adolescent's life are not ignored. However it should be remembered that the needs assessment is part of the process of forming a trusting relationship, and it is important that the form does not become a barrier in the conversations being had. See Appendix Five for an example of a framework for assessing the needs of a child.

transpired that they were not taking their medication or were struggling with their own mental health. It is immensely important to remember that mentors may need a high level of support themselves and that their needs, as HIV positive young adults, should not be overlooked.

The mentor, whether working in a voluntary or paid capacity, should be treated as a member of staff. To that end they should receive supervision, debriefing, and be expected to work under the organisation's policies, including receiving training in child safeguarding.

### Policy considerations

One-to-one work will sit closely with an organisation's child protection and safeguarding policy. A policy relating to one-to-one work should consider:

**a) Assessment process.** This will outline the assessment process – how assessments are recorded and stored securely – and the review process, which will ensure a focus on solutions and positive outcomes.

**b) Lone working.** This will set out how lone working takes place, for example, home visits and community outreach work, outlining protective procedures for both the child or adolescent and the staff member.

**c) Regular supervision.** This will include how often supervision takes place, who takes responsibility for recording supervision to ensure accountability and



provide evidence of work. Supervision should include space for the worker to reflect upon the emotional impact of the work.

**d) Use of Peer mentors.** To ensure peer mentors have appropriate support, supervision and training, including the expectation that they work in accordance with all the organisation's policies.

**e) Staff and volunteer training.** Staff, peer mentors and volunteers receive up-to-date training on issues such as safeguarding and child protection. The organisation should also ensure that they are aware of key policies such as anti-discrimination or equality and inclusion policy and behaviour management policy.

### Policy checklist: One-to-one work with children and adolescents

- Assessment process
- How and where one-to-one work will take place
- How records of work are kept
- Supervision should be available to those undertaking the work
- Support, training and supervision of peer mentors
- Training for staff, peer mentors and volunteers on organisation policies



## 4.8 Group work

*Watch video: The impact of having access to peer support - <http://vimeo.com/112425897> (password: chiva)*

For group work to effectively support the impact of HIV on children and adolescents, whether they are infected or affected by HIV, it is necessary for the child or adolescent to have complete knowledge of HIV.

It is clear that children who are affected by HIV often need access to support to help them with the impact that HIV in their family has on their lives.

Practice experience in the UK has shown that the needs of these two groups are distinct and that peer support works most effectively when these groups are supported separately.

Peer group work needs to explore specific issues relating to HIV in a dynamic,

child-centred and fun way, combining discussion and exploration of feelings, views and experiences with games and leisure activities. It should be a safe and non-judgemental space where feelings and fears can be explored.

It is key to remember that for many ALHIV this may be the only place they feel able to express how they feel about their life with HIV and therefore they may withdraw or exhibit challenging, disruptive behaviour. Although this needs to be managed in line with the group's agreement on behaviour, facilitators should be aware that this probably means that the ALHIV needs additional one-to-one support outside of the group.

Group work is most effective when it is carefully planned, in consultation with the ALHIV who will be accessing it, which will ensure their needs are being responded to. It is important that HIV has

a regular and explicit presence in group work sessions, whilst recognising the ALHIV may have other issues they wish to address here.



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Experience from the UK of running peer support groups with ALHIV has found a mixture of themes to be most affective. Sessions can combine fun-based activities that build relationships and support self-esteem, with activities that encourage self-expression, explore HIV related issues or are therapeutic. Section Four sets out different models of peer support work and Appendix One offers numerous activities that can be run in this context.

Alongside professionally delivered support, C&ALHIV need to be encouraged to build their own support networks with each other. These peer networks can empower ALHIV to cope better in their lives and not become overly dependent on professionals. Peer support groups can be very effective in supporting the development of peer networks as well as providing a place to share experiences of a life with HIV.

### Policy considerations

A group work policy can consider including statements concerning the following:

**a) All attending are fully aware of their HIV status or how they are affected by HIV (i.e., who in their family has HIV if not themselves).** This statement can

include how to ensure all adolescents who attend the group are fully aware of how they are affected by HIV, whether they have HIV themselves or a member of their family does.

**b) Group work sessions are planned in advance with clear aims and**

**desired outcomes identified. HIV is assured a regular presence in group sessions.** Ongoing consultation with adolescents in the group will ensure the group remains responsive to new and developing needs, and that the group feel a sense of ownership of it.

**c) Groups will have an agreed behavioural agreement and ground rules.** ALHIV and staff need to agree this; the disciplinary steps need to be fair and agreed. This should be made very clear to the ALHIV.

**d) A statement about equality and access for all.** To ensure all ALHIV can fully participate.

**e) Staff training and support.** Ensure staff are trained in child protection and safeguarding and child-centred practice, with clear understanding of children's

rights. Staff should receive regular supervision and be expected to uphold appropriate boundaries. Staff will benefit from regular training about HIV to ensure their knowledge and understanding is current, and to develop confidence in talking about HIV.

**f) ALHIV are central to evaluation and development.** It is useful to evaluate group work sessions. This helps to ensure the participation of ALHIV, to enable an assessment of whether their needs are being met in the group, and to enable contribution of new ideas and suggestions to support development and planning.

**g) Risk assessment.** Plan for the management of any potential risks of harm by carrying out a risk assessment (see Appendix Five).

### Policy checklist: Group work

- HIV infected and affected adolescents supported in separate groups
- All attending must be fully aware of their HIV status
- Groups are planned with clear aims and outcomes identified
- Specific aim to support knowledge and understanding of HIV
- Group rules to support behaviour
- Staff training
- Groups are risk assessed and evaluated
- All groups and activities are child-focused



## 4.9 General practice points

There are a number of general practice points that need consideration when

developing services that will engage and support C&ALHIV.

### Referral process

Have a clear and effective referral system that can include a simple form for

practitioners to complete, but that also has the capacity for a child or parent/

carer to make direct contact with the service. This can include eligibility, such as whether the child has full knowledge of their HIV diagnosis for accessing

groups and whether the referral is to access support for any specific issues such as onward disclosure or adherence work.



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It is very important to consider how a service responds once they receive a referral. Have an agreed timeframe, for example all referrals will be responded to within two weeks and someone from the service will meet with the child within a month. Set these time frames with respect to the organisation's capacity and consider the need to prioritise access based on the child's needs. The practitioner or parent/carer may have worked very hard to convince an

adolescent to engage with your service, so a quick response is important. When a child or adolescent refers themselves, an organisation should acknowledge and respect this by responding promptly.

To enable access to the service it is important to promote and publicise it. This may be done in clinic waiting rooms or more widely through broader professional settings.

## Supervision

People working with C&ALHIV should receive regular supervision. This is a time for them to be able to confidentially discuss any issues or complexities that have arisen and be supported in either locating solutions or managing their personal responses. Supervision helps

to protect against the emotional impact of the direct support work with C&ALHIV and their families. It helps to maintain safe working practices. If individual supervision is not available, facilitated group supervision will support staff to share their concerns and find solutions.

## Record keeping

It is important that clear records are kept on contact and work with C&ALHIV and their families. Records ensure transparency of work practice and accountability and also mean that if a staff member leaves, there is a record of the work they have undertaken.

Records for group work should include when groups are run, who attended, what was covered, the evaluation, and any individual concerns that may have arisen during the group and what action has been taken.

One-to-one work records should include where the meeting took place, what was discussed, any actions needed and any concerns. These records should be stored securely and only accessible to those who need to know the content.

It is also useful to have forms which record any incidents that occur, accidents, child welfare and child protection concerns.

## General practice considerations checklist



- Clear referral process to access the service with response time targets
- Supervision provided for workers
- Records kept about all contact work with C&ALHIV



## SECTION FIVE: EXAMPLES OF UK PRACTICE

This section sets out different models that have been successfully used to work with C&ALHIV in the UK. The activities set out in Appendix One have been run in one or more of these contexts. The models offer different structures to

ensure the support needs of all C&ALHIV are met, whether they live in high or low prevalence settings or whether they are geographically isolated. Different models also reflect different financial constraints.

### 5.1 Peer support groups

Peer support is defined as facilitated group work undertaken with a group of C&ALHIV. This approach is based on the understanding that the sharing of experiences with a group of peers, who share the challenges of HIV, enables empathy and understanding. This shared experience supports the capacity of all members of the group to manage the challenges in their lives. Peer support

can enable the sharing of practical strategies, such as to support medication adherence, and the sharing of social experiences, such as telling a partner or friend about HIV. It has been an important model for work with ALHIV due to the stigma attached to HIV and the feelings of isolation this group can experience.

The examples below have the following in common:

- All adolescents involved are HIV positive and fully aware of this
- All staff are experts in HIV
- Activities have therapeutic value but are delivered using a range of approaches such as drama, art, performance and writing poetry.

ALHIV should be consulted in the development of a group, but this needs to be undertaken within the constraints of the reality of the lives of ALHIV, finances, geographical spread of the potential users, staff and facilities available. Some groups may have a regular space that they can access for peer support group meetings and be able to develop that space as their own, putting up pictures and information. Others may have to share a space or use somewhere provided by other organisations, community groups or faith organisations.

In the UK, some peer support groups run weekly, monthly, during school holidays, three times a year and once a year. Where regular peer support groups are not possible, other approaches such as occasional groups can still provide invaluable opportunities for developing peer support networks and gaining a better understanding of HIV. As ALHIV live healthier and fuller lives, less regular HIV peer support may become more desirable.

The main aim is to provide a support group for C&ALHIV and not simply the



opportunity for socialising. As such it is important to have a structure that always acknowledges what the group is for

and that staff facilitation supports open discussions about HIV.

### Case Study: Barnardo's (Gregory's Place)

Gregory's Place facilitates two monthly peer support groups for C&ALHIV where every child attending must know their HIV diagnosis. ChiPS (Children's Peer Support) is for 11–16 year olds and runs at the weekend. PSG (Peer Support Group) is a group for 16–19 year olds and runs monthly during an evening.

Each ChiPS and PSG session lasts for two hours and takes place in a room that is bright and comfortable with the C&ALHIV's artwork displayed on the walls. Food is provided at each session.

The purpose of ChiPS and PSG is to deliver age appropriate HIV information sessions to increase confidence, understanding and knowledge of living with HIV. Examples of sessions run here can be found in Appendix One and include 'HIV and the Immune System' and 'Talking to others about HIV'.

Structure of each session:

- Arrival, drinks and an ice-breaker (30 minutes)
- HIV information session (45 minutes)
- Food and social time (30 minutes)
- Future group dates, activities and departure (15 minutes).



Every individual has a different learning style and young people tell us they do not want the groups to be like school. Therefore, all sessions are interactive, creative and engaging. When funding is available, we combine these groups for trips, residential weekends and have made videos and participated in drama workshops.

Gregory's Place is a children and HIV project run by Barnardo's that has worked in Greater Manchester for 15 years. Barnardo's is an NGO working across the UK supporting children.

## 5.2 Residential interventions

There is a wide practice of providing residential camps/holidays for groups of children and adolescents as these have been shown to provide a range of social and educational benefits. A residential

break specifically for C&ALHIV is an excellent opportunity for a therapeutic intervention to explore psychosocial issues and encourage open conversations about HIV within the peer group.

An overnight stay allows for experiences that a regular group cannot. For example, being able to take medication openly with peers can be a profound experience. Spending intensive time with a peer group, which includes team-building, workshops, sharing bedrooms and late night conversations sharing experiences of HIV can develop strong bonds between adolescents that will continue long after the residential is over.

Residential interventions are a good model to consider in low prevalence settings or where C&ALHIV are geographically spread out. They can be costly, but there are significant health and well-being impacts, which should be stressed when seeking funding [19].

### Case study: Freedom To Be (F2B)

Since 2010, the Children's HIV Association (CHIVA) has been running an annual 5-day residential intervention for 100 ALHIV aged between 13-17 who know their HIV diagnosis. This is open to all

across the UK and Ireland and places are allocated on specific criteria to prioritise the most isolated and offer all ALHIV the opportunity to attend once.

There is a structured programme that includes:

- Mandatory youth-friendly HIV workshops (many included in Appendix One)
- Therapeutic creative activities such as art, dance, drama and singing
- Complementary therapies
- Outward bound physical activities for team building and self-esteem
- Single-sex sexual health and relationship sessions.

The number attending means that there is a large impact on the experience of isolation simply due to the critical mass of ALHIV present. Being able to look around and see all these people that share the same experience of growing up with HIV has been reported as having a profound impact on attendees [20]. Having only ALHIV attending who know their diagnosis means that HIV is talked about openly and becomes 'normal'. This is a unique opportunity for ALHIV.

The camp venue staff are trained prior to F2B running, to raise awareness

about HIV, dispel any fears and ensure confidentiality. F2B is run by six CHIVA staff and a team of 25 volunteers, 50% of whom are HIV positive. There are also 10 HIV positive young adults who are trained as Camp Leaders, being mentors and supporting the running of F2B.

CHIVA is both a network of people providing medical care and support for C&ALHIV and a service provider. For more details and to read the evaluations of F2B, please visit [www.chiva.org.uk/supportcamp](http://www.chiva.org.uk/supportcamp)

The case study of F2B above offers an example of a large residential intervention, but smaller residential interventions are also extremely effective where there is a low number of

geographically isolated C&ALHIV. Prior to F2B, CHIVA ran 3-day therapeutic residential for 30 ALHIV.

### 5.3 Occasional sessions attached to clinics

Where there is no funding or organisations available to run a regular peer support group, or where ALHIV do not want to engage with services outside of health, clinics have developed occasional group

work models. These use youth-friendly activities to explore issues relating to growing up with HIV and involve other professionals who are able to come and assist in facilitating particular sessions.

#### Case study: 'Looking forward' young people's days

'Looking Forward' days are open to ALHIV aged between 12-18 years who are aware of their HIV diagnosis. The session evolved as part of the transition process of moving adolescents into adult care.

These days run during school holidays four times a year. Initially, a letter is sent to the parent/carer telling them their child will shortly be invited to the day. The letter includes information about what has been planned to happen that day and what topics will be covered. The ALHIV are then sent two invitations and a telephone reminder prior to the day.

The day is held in a local church away from the clinic setting, which is easy

to access on public transport. The day programme involves a multi-disciplinary team and covers topics such as 'What is HIV and what does it do?', 'Adherence to medication', 'Becoming a teenager', 'Sex and sexual health' and 'Negotiation in relationships'. Each session is interactive and although there is a basic structure, the adolescents drive the direction of the sessions.

'Looking Forward' is run by Newham Primary Care Trust, that is an NHS health care provider.

### 5.4 Therapeutic creative activities

Adolescents may respond more positively to creative art approaches, where feelings can be expressed through art forms. These can be particularly effective for those who find sitting and talking uncomfortable and can support the building of self-esteem and self-worth in ALHIV.

There may be opportunities to collaborate with other charities or arts organisations to undertake one-off or ongoing creative activities that also serve to raise awareness about the issues faced by C&ALHIV more broadly.

### Case Study: Art is Key

CHIVA formed a partnership with Turtle Key Arts to run a week-long arts project for 20 ALHIV called 'Art is Key'.

Turtle Key Arts is a professional theatre company that undertakes community arts projects. Professional artists were recruited to work with small groups of ALHIV throughout the week to develop a performance piece which was created by the ALHIV and reflected their processing of the impact of HIV on their lives using performance.

The art forms used were dance, music performance, song composition, drama, poetry and technical set design. The workshop and performance took place in a youth arts venue with a professional theatre. Friends and families of the ALHIV

and the organisation involved were invited to watch the performance.

Key benefits for ALHIV were the opportunity to work with professional artists and to explore HIV in a safe space using creative expression. The opportunity to 'show' their work supported self-esteem and inviting parent/carers to attend enabled a sharing and communication of feelings around HIV that can be challenging for some families.

Turtle Key Arts produces, manages and devises performance arts projects with a particular emphasis on original and groundbreaking work.

<http://www.turtlekeyarts.org.uk/>

### 5.5 Advocacy and influencing policy

Article 12 of the UNCRC states that:

'...the child who is capable of forming his or her own views has the right to express those views freely in all matters affecting the child....'[21]

Historically, there has been limited opportunity for C&ALHIV to contribute to the formation of policies and development of services that affect their lives. This can be understood in the context of the challenges around C&ALHIV's knowledge of their own HIV

status and access to open conversations about HIV.

Facilitating C&ALHIV's participation in the planning and development of services and policies and practice that affect them, is an important aspect of a child rights approach. Such participation opportunities should not replace the provision of psychosocial support for C&ALHIV and both need to be available.

Where a child or adolescent wishes to take up participation opportunities, they will need support and preparation to do this. This can include:

- Providing training, such as public speaking or working with the media
- Ensuring key issues such as confidentiality are understood by all involved and that ALHIV have control over this.

The sharing of personal stories can be a useful means to convey an understanding of the impact of HIV on children and adolescents. This should be balanced with an ability to 'represent' the broader experiences of a wider group of C&ALHIV, to ensure a balanced representation of needs and views.

### Case Study: The CHIVA Youth Committee (CYC)

In 2009, CHIVA developed a Youth Committee to give ALHIV a national voice in developing healthcare practice. This has now extended to incorporate advocating for C&ALHIV across the UK in the children's sector, national policy and the general public through the media.

The CYC consists of 12 ALHIV aged between 13 and 18 all of whom know their HIV diagnosis. They represent different regions of the country and different experiences of HIV, coming from urban and rural settings, living with biological parents, family members, foster carers or having been adopted. They are recruited for a minimum of two years and must be interested in representing their peer group and making a difference for other C&ALHIV. The current CYC do not favour a formal election process so applications to be a member are anonymous and current members selected on the basis of ensuring a fair representation across age, gender and geographical location. There are specific roles such as Chairperson and Media Officer.

The CYC meets four times a year for two days and one night. They have their own projects and campaigns, including

an anti-stigma Twitter campaign (@freedom2spk). They are youth representatives on research studies and clinical trials, on national youth participation groups, they comment on clinical guidelines and undertake public speaking. They also undertake media work, in which currently all wish to be anonymous. They have been involved in international work at UNAIDS and the International AIDS Conference.

The ethos behind CYC is to empower ALHIV to be as active as they wish and engage with topics and issues they feel passionately about. They are advocates and this is central to the work they undertake, using social networking and face-to-face meetings to feed back to their peers.

The CYC are supported by a part-time Participation Officer who manages their work programme, their meetings and travel arrangements and who liaises with outside contacts and the media on their behalf.

You can find out more about the CYC at [www.chiva.org.uk/cyc](http://www.chiva.org.uk/cyc) or by emailing [youthcommittee@chiva.org.uk](mailto:youthcommittee@chiva.org.uk).

### 5.6 On-line activities

Children and adolescents access the Internet and social media through their mobile phones, computers, games consoles and tablets. In the UK, many different online forums have been

developed, but from our experience, the most successful are those that ALHIV set up themselves after having met with each other. The UK learning from this area is that nothing can take the place of the

opportunity to meet face-to-face with your peers. Social media then works to keep ALHIV in contact with one another.

The Internet does offer the facilities to create information hubs where C&ALHIV can go to access correct, relevant and youth-friendly information about growing up with HIV. It offers a

resource where they can have questions answered and better understand HIV. It is important that this information is directed by C&ALHIV to ensure it meets their information needs and is written in a way that can be easily understood, using multi-media approaches to keep it dynamic.

### Case Study: A secure website for C&ALHIV

'If only you knew' (IOYK) is a private login-only accessible website for C&ALHIV. It was developed in 2009 with a group of over 30 ALHIV, who were involved in the design, layout and content of the site, writing some of the copy. The rest of the site was written by experts from different fields (health, social care, law and human rights) and then simplified to ensure it was understandable.

The content of the site is split into three different age groups: under 12, 12-15 and 16 plus. The copy is generally the same, but written for differing levels of maturity. The older ages include more detailed information about sex and relationships and as ALHIV were involved in the entire process, the information is tailored to exactly what they said they needed to know.

There are also several pages that serve as an audio-visual archive of previous residential and the annual CHIVA

support camp, where there are photos, videos, magazines and music.

We have experimented with providing features that allow members to interact, such as a profile page, a chat room and an on-line forum. Up to now, we have found that although through consultation ALHIV are keen for these to be provided, in reality, the main social media they use are those they have created themselves once they have met their HIV positive peers. Our conclusion is that the information resource specifically for C&ALHIV is essential, but that time and money is better placed in organising face-to-face meetings, following which the ALHIV will link themselves through social media.

Further information can be found at [www.chiva.org.uk](http://www.chiva.org.uk)

## 5.7 Consultation with ALHIV

All the examples of practice above have consulted with C&ALHIV, to ensure that the services developed meet their needs and that they have ownership over these. When consulting with this group, whether in relation to setting

up new services or developing existing ones, these are some areas that require consideration:

- Work with doctors and nurses, as clinics are where you will find all the C&ALHIV.
- Offer them something they want or need, whether this is meeting up with others, fun activities or basics such as a hot meal.
- Be imaginative and use different methods to engage them. Some will prefer an online questionnaire on a tablet computer, others a one-to-one interview; some will enjoy getting together as a group whereas others may respond to an outing to an amusement park or a Christmas party.
- Never presume literacy. Use art, drama and physical activities to engage them in the process and if someone responds badly to written activities, it may just be because they struggle to read or write, so always have other possibilities available.
- Always place consultations in the realities of the context: what money is available, what facilities you have access to, and staffing levels. Be honest from the beginning and do not promise things you cannot provide.

### Questions to ask in a consultation:

- What support do you feel you need?
- Where would you like that support to happen?
- How often and what times of day would suit you?
- If a group is geographically isolated, ask them 'how would you bring this group together?'

Remember how fearful many people are about talking about HIV. C&ALHIV may say 'we want to go bowling and for pizza,' but this might be because they have never been allowed to openly discuss and ask questions about HIV. HIV support

groups must do this and empower these children and adolescents to be able to manage a life with HIV without fear.





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## APPENDIX ONE: ACTIVITY SHEETS TO USE WHEN WORKING WITH C&ALHIV

Watch video: Talking to a child about HIV demonstration - <http://vimeo.com/112425743> (password:chiva)

Watch video: Condom demonstration - <http://vimeo.com/112431683> (password:chiva)

What follows are a number of examples of activities that the authors have run with groups of ALHIV. Many can be used

to explore various HIV (and non-HIV) related issues.



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### Adherence

1. Adherence and aspirations
2. Me, My Health and I
3. Medication workshop

### Knowledge and understanding about HIV

4. Agony Aunt
5. Fishing for answers
6. Quiz

### Personal experiences of HIV

7. Comic strip
8. Boxes
9. Game of life
10. Life map
11. What people know

### Self-esteem and well being

12. Giving and receiving compliments
13. Identity shield
14. My future

**Sex and sexual health**

15. Sexual Health Session
16. To tell or not to tell
17. Blind date (condom use)

**Stigma and self-stigma**

18. Drama activity
19. Poster campaign
20. Re-branding HIV
21. Understanding Stigma

**Talking to others about HIV**

22. Decision corner
23. Talking to others

**Warm up and ending games**

24. Warm up and team building games
25. Games to run after therapeutic sessions

## 1. ADHERENCE AND ASPIRATIONS

**Estimated time:** 1 hour

**Who:** minimum 6

**Learning Objectives**

- To get the young people to think about why at times in their lives they may decide to not take their HIV medication
- To focus on future aspirations

**Materials/equipment (Handouts)**

Have 5 x A4 sheets with one of the following pictures on each: a pill, a sick person, a well person, a '+' sign and an '='

A4 sheet for each participant and arts and crafts materials

**Session Overview**

This is a workshop session that has a number of activities in it to take the participants through a process that considers adherence in the context of their life and future aspirations. The hopes and dreams exercise may seem simple, but many ALHIV do not feel they

have a future and this exercise shows that they do and should have dreams and aspirations. HIV medication is then linked to a future which with identified hopes and aspirations.



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### Activity

#### Exercise one

1. Stick to the wall the following equation:  
 $\text{'Ill person} + \text{pill} = \text{'}$   
 Question: Who here has ever taken medicine (other than HIV medicine) Perhaps you've had a chest infection, or an earache. When you feel ill and someone says 'take this medicine, it will make you feel better' what do you do?  
 Now stick the "*well person*" after the '=' sign.
2. Next equation:  
 $\text{'Well person} + \text{pill} = \text{'}$   
 Question: How many of you here have felt completely fine, but someone says 'you need to take this medicine to stay well'?  
 Let them answer and then leave this on the wall.

#### Exercise Two- Asking questions

3. Question 1: Why do you think this second equation is more difficult than the first one?  
 Question 2: What have people told you in the past about why you should take your HIV medicines? Ask the group to shout out their answers and write these up on one piece of flip chart.  
 Put this piece of flip chart over the '*well person*' on the equation.  
 Question 3: How have the things you have been told about why you should take your medicine made you feel about medicines? Write these answers on another piece of flip chart and put this at the end of the equation after '='.  
 Question 4: 'Why do HIV positive young people sometimes not take medication?' Write up answers but also ask follow up questions to get them to explain in more depth and think it through

### Exercise Three: Hopes and dreams

4. On a piece of A4 ask them to draw a picture of themselves in the bottom left corner and draw a path running up to the top right (have example ready). Explain the path is a timeline, so at the beginning it's their hopes for today or this week, then for the next few years and at the end, their hopes for when they are really old. They can put down what ever they want, and do not have to explain it.  
Once task is finished, put all pictures up on the wall and ask if anyone is happy to share one thing from their picture with the group.  
As they speak, write one or two words on a piece of flip chart changing the colours of the pens, so end up with a medley of 'hopes and dreams'.
5. To conclude, ask: What do you think is the connection between the 'equations' and these 'hopes and aspirations'?

### Facilitation Points

- Make sure you either write up ground rules for the group or if you already have these set, refer back to them. It needs to be stressed that this is a safe space to share the truth, rather than saying things you think people want to hear. Be clear you will not be report back to their doctor, parent or guardian when they talk about why they do not or have not taken their medicine in the past.
- The key outcome is to get this group to think about their futures and see that they have one – but it is one achieved with medication and medication is their friend in this. Ensure the ending is uplifting so anyone who struggles with taking their medication will go away feeling more positive.

## 2. ME, MY HEALTH AND I

**Estimated time:** 45/60 minutes

**Who:** minimum 3, maximum 15

### Learning Objectives

- To explore the things that are important to the ALHIV
- To consider the link between these important things and them keeping well
- To see that their medication keeps them well which means they are there for the important things in their lives

**Materials/equipment (Handouts)** Paper, pens/pencils.

Adolescents Living with HIV:

**Developing and Strengthening Care and Support Services**



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## Session Overview

This session explores the links between the things an ALHIV values and are important to them and keeping themselves well and taking their HIV medication.

Activity	
1	<b>Exercise one:</b> Explain that we have lots of different 'relationships' in our lives with people and things. Give each ALHIV a piece of paper and divide it into four. In each square either write or draw the answer to the following <ul style="list-style-type: none"> <li>• A person who is important to you</li> <li>• Your favourite possession.</li> <li>• Something you like to do.</li> <li>• A place you like to go</li> </ul>
2	<b>Exercise two:</b> Ask the group: <i>How do you take care of these things?</i> Get them to draw or write one way they take care of each of these four things. For example: Person is my mum, I make her tea. Place is my bedroom, I should tidy it etc
3	<b>Exercise three:</b> Ask the group: <i>What would happen to these important things if you were not well?</i> Ask them to either write or draw this in each of the four areas of the paper. Ask each ALHIV (if they are happy to) to share their picture, explaining their answers and pictures. Put all pictures up on the walls. If there is not time for everyone to share what they have done, put the pictures up and let the ALHIV have a look at them for 5 minutes.



**4 Exercise four:**

Ask the group: *How do you keep yourself well?*

In one colour pen, write the answers up on a piece of flip chart and get them to discuss personal hygiene, diet, exercise and medication.

Ask the group: *What helps you do all these things?*

Go through each example the group gives and in a different colour pen, write this next to the example.

Ask the group to reflect back through the exercises, helping them find the link that medication is something that keeps you well so you can take care of the things that are important to you. Use the word 'relationship' and how they need to develop a relationship with their HIV and with their medication – it is just like the other relationships they have in their lives with people and things.

**Facilitation points:**

- This exercise is about seeing medication as something that is like eating, exercising, washing.
- Everything in our lives is linked together and HIV is part of ALHIV lives, it does not define them, but it is part of them. Help them to normalise HIV and medication into their lives, rather than seeing it as a separate thing.
- Focus on the positives, if you keep well then you are also taking care of the things you love in your life, whether that is a person, playing football, music, dance etc – it is all linked and you are the link.

**3. MEDICATION WORKSHOP**

**Estimated time:** 30-40 minutes

**Who:** minimum 4

**Learning Objectives:**

- Understanding how medication works, the barriers and benefits to taking medication.

**Materials/equipment (Handouts)** Flip chart paper, pens.

**Session Overview**

This exercise encourages peer support. The adolescents are asked to identify and share the reasons why they may find it difficult to take their medication and then think about what they can do to help this.

This also provides an opportunity to look at the benefits to taking medication and ways to keep healthy.

Adolescents Living with HIV:

**Developing and Strengthening Care and Support Services**



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Activity	
1.	Adolescents get into pairs and each pair are given a flipchart paper and pen.
2.	Ask them to talk about and write down all the things they DON'T like about taking medication. Allow 10 minutes for discussion.
3.	Then ask them to talk about and write down next to each point what helps them to cope with this, e.g Big pills = certain drinks / yoghurt, Feeling sick = take before bed or with food. Side affects = talk to your Nurse/Consultant, Forgetting to take medication = using alarms.
4.	Bring the group back together and facilitate a discussion with each pair feeding back on their list of medication issues.
5.	In the large group, ask adolescents to call out the reasons why they take their medicine and write these up. Include time for clarifying reasons, health benefits etc. Facilitator to write on flipchart.

### Suggested questions for discussion

1. What don't you like about taking your medication?
2. What are your worries about taking medication?
3. What are the consequences of not taking medication?
4. How does the medication help you to improve your health
5. What else can you do to improve your health



### Facilitation Points

Encourage discussion and use prompts to help i.e. medication can make you feel different from other people...and then provide some information on the range of health issues adolescents may be taking medication for.

Ensure you explore the positive side of taking medication, and treatment

developments. Try to promote a positive and hopeful end to the session.

This activity was developed by THT Nottingham, UK, and Faith in people with HIV, Leicester, UK.

## 4. AGONY AUNT

*Agony Aunt letters* are letters sent in to a newspaper or magazine and people ask for help with problems or worries. The letter and response are then published.

**Estimated time:** 30-45 minutes (depending on quality of discussion)

**Who:** Group of 4-8

### Learning Objectives

- To facilitate group discussion about HIV specific issues relating to relationships, sex and talking to others about HIV
- To increase understanding on these issues and support ALHIV to think about the issues relating to sex, relationships and talking to others about their HIV

**Materials/equipment (Handouts):** Write three "Agony Aunt" letters. You can use example ones suggested below or alter and make your own.

### Session Overview

This is an activity that can be used as part of a session to explore specific issues relating to relationships, sex and HIV. You should write 'Agony Aunt' letters before the session, ensuring they are written in the way the adolescents speak (you can take them from magazines and then change them to make them HIV specific). Letter one should not be about HIV, but

a general youth/relationship issue to help the group warm up. The other two will be specific to HIV, sex and talking to others.

### Activity

- |   |  |
|---|--|
| 1 | <p>Explain that the group are all Agony Aunts that get sent letters and need to give advice.</p> <p>Ask for a volunteer to read the first letter to the group.</p> <p>After each letter ask, what advice should we give that adolescent?</p> <p>In the discussion, ask the ALHIV to expand or explain answers.</p> <p>Ask for a volunteer to read out letter two, then discuss</p> <p>Ask for a volunteer to read out letter three, then discuss</p> |
| 2 | <p><b>Reflections</b></p> <p>Ask the group what they thought about the activity. Was there anything they found difficult and has it made them think about anything relating to their own experiences?</p>  |

### Facilitation points

- It is important to facilitate the discussion after each letter so that they explore the complexities of this area of their own lives. If the ALHIV says 'tell the person' then ask them:
- How should the adolescent do this?
  - What advice would you give them if the person responds badly?
  - Are there any other options that person has?
- There are no right or wrong answers, this is about giving the group the space to explore how they might respond to situations as and when they arise in their lives.



### Example letters

Start with a letter which is fun and the group can engage with:

Dear Aunt Agona (*put in a well known agony Aunt or make up a name*)

I am 13 years old and I really fancy this girl but she won't ever look at me. How can I make her notice me as I'm not very confident and when I see her I get shaky and can't speak.

I'm desperate,

Peter





Dear Aunt Agona

I was at a party recently and the friends I went with took a bottle of vodka with them. They all started drinking and I felt like I had to join in too although I didn't really want to. I got really drunk and sick. I can't remember what happened at the end of the night but I woke up in one of the bedrooms upstairs. I didn't have my trousers on. I'm 14 years old. What should I do?

Help me!

Joseph

Dear Aunt Agona

I found out I've got HIV a year ago. It was a real shock and I didn't really know what that meant and what I should do. I've learnt now that lots of people live really well with HIV and as long as I take a bit of care of myself, I should be OK. But I also read on the Internet that I might die of AIDS. What is true?

Feeling confused,

Sarah

Dear Aunt Agona

I met this boy three months ago. He's really kind and caring and I think he really loves me. We have sort of had sex, but I got freaked out. Should I tell him I have HIV? I feel like I should, but then I'm so scared that he might just split up with me, and worse than that, tell everyone. What should I do?

I'm worried,

Ruth



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## 5. FISHING FOR ANSWERS

**Estimated time:** 30-45 minutes

**Who:** minimum 4

### Learning Objectives

- To share experiences and talk openly about HIV
- To learn more information about specific aspects of living well with HIV

**Materials/equipment (Handouts):** Make a fishing rod using a stick, a piece of string and bending a paper clip for a hook. Questions written on fish shaped card with paper clips stuck to the back so they can be hooked out by the fishing rod.

### Session Overview

This is an activity to explore issues relating to living with HIV. Such as talking to others about HIV, taking medication, thinking about the future. It encourages participants to share their experiences, hopes, fears and provides an opportunity to increase knowledge and understanding. Have

a few 'silly' questions included as well – this encourages some humour and helps people feel relaxed.

### Activity

- 1 Ask the group to sit in a circle and the fish shaped questions are put face down on the floor.  
The 'fishing rod' is passed around the group and members try to 'catch a question'.  
They can either choose to answer the question they catch or open it out to the group.

### Examples of possible questions:

#### 1. Have you ever talked to a friend about being HIV positive?

*Discussion prompts:*

- If no, why is this?
- What do you think would help you decide how to talk to friends about being HIV positive?
- Who would you go to for help?
- How would you plan this?
- If yes, why did you tell them? how did you tell them? and what was the outcome?

#### 2. Do you think about being a parent in the future?

*Discussion prompts:*

- What do you need to know about this?
- Has anyone ever spoken to you about safe conception?
- Where would you go to find out?

#### 3. Have you ever not taken your medication?

*Discussion prompts:*

- If yes, can you think about why that happened?
- What do you think helps you to take medication?

#### 4. Can you explain what HIV is and what AIDS means?

*Discussion prompts:*

- Help to fill in any gaps in knowledge.  
Check transmission knowledge is correct.

### Facilitation Points

- If there are literacy issues in the group, you can ask for volunteers to read out the questions from the start, but the person with the fishing rod is to answer them.
- After each question is answered, ask the whole group for any other thoughts or experiences





## 6. QUIZ

**Estimated time:** 30 minutes

**Who:** minimum 6

### Learning Objectives

- To improve participant's factual knowledge of HIV.
- To establish a general awareness about HIV and get ALHIV used to hearing it and talking about it.

**Materials/equipment (Handouts):** Quiz sheets, pens and a prize

### Session Overview

This activity uses a quiz to achieve basic knowledge and understanding about HIV. The questions and answers ensure correct knowledge at a basic level is gained and the discussion after

each answer allows time and space to explain details and correct any misunderstandings. This is a good warm up activity with a new group of ALHIV.

Activity	
1.	Depending on the size of the group, divide them into pairs or teams. Ask each pair/team to make up a name for themselves.
2.	Hand out one answer sheet per pair/team
3.	10-15 question quiz
4.	Ask them to hand their sheets clockwise for marking and then discuss the answers, getting the ALHIV to say what they thought and correct or add additional information where needed.

### Facilitation Points

- Make this exercise fun and competitive as this can provoke lively discussion.
- When you come to the answers, get the ALHIV to give the answers and if an answer is not right, see if anyone in the group knows the right answer.
- With some answers, use it as a way to get the group talking about facts and also things they have heard or been told about HIV that are not correct. This way they are openly discussing HIV, which for many may be the first time they have done this.
- This is a good activity to assess the knowledge levels within the group.



### Possible questions

Below are just suggestions to help with planning a quiz. Use this as a guide but create your own questions which are relevant to the context in which you work.

#### Round one: Basic facts

1. Who travelled the furthest to be here today?
2. What does H.I.V stand for? *In the answer stress this is a virus*
3. What does A.I.D.S stand for? *In the answer, stress that A.I.D.S isn't **an illness**, but a syndrome, so a group of different illnesses, when a person has had one of these specific (HIV associated) illnesses they may be given an AIDS diagnosis.*
4. Name 3 places (ie fluids) where HIV can be found in the body?
5. Name 3 ways in which you can be infected with HIV?

#### Round two: Data

1. Approximately how many people are infected with HIV in your country?
2. If a woman is HIV+, what is the probability of her having an HIV+ child?  
You can give 4 options: 1 in 1 – every child will be positive,  
1 in 4, 1 in 25, **1 in 100** (*Explain carefully in your answers that transmission rates are 1 in 100 where the mother has access to **prevention interventions** and be clear what these are*)
3. How many HIV+ under 19s live in your country?

#### Round 3: TRUE/FALSE

1. Under the law in your country, you have to tell your employer/school if you have HIV? *In the answers explain who does and does not have to be told and why.*
2. There is a cure for HIV? *In the answers talk about Post Exposure Prophylaxis. Enable participants to share their own thoughts or understanding about the possibility of a cure for HIV.*

## 7. COMIC STRIP

**Estimated time:** 1 hour

**Who:** Any size group

### Learning Objective

- Use this activity to explore an issue related to living with HIV
- Use art-based processes to give ALHIV the opportunity to express themselves and share their experiences and feelings

**Materials/equipment:** Flip chart paper, paper, pens, art equipment, scissors, magazines

### Session Overview

This is a simple activity that can be therapeutic, giving ALHIV a voice in whether enabling them to tell their stories, produce something for wider public viewing or used as a consultation

exercise. The idea is that they each make their own comic strip story. Below illustrates this activity using the example of Stigma.



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#### Activity

##### 1 **Getting the group thinking**

**Aim:** Explain the focus of the session and the issue you are going to explore.

Ask the group '*what is stigma?*'

Ask the group to shout out what comes into their mind when they think about stigma and HIV. Ask for short quick answers and write these on a piece of flip chart paper.

Now go through the answers and ask the group to give any examples from their experiences or to elaborate on what they said.

2	<b>Making a comic strip</b>
	<p>Talk through with the group the process of making a comic strip. Write up the process:</p> <p><b>PLANNING</b></p> <ul style="list-style-type: none"> <li>• Plan your story, all stories need a beginning, a middle and an end</li> <li>• Decide on your characters</li> <li>• Decide on the point you want to make – comic strips are simple and tend to make one or two points or key message</li> <li>• Make a rough sketch of your comic and how you will set out the story</li> </ul> <p>Now use whatever materials you like to make your comic strip</p>
3	Put all the comic strips around the room, either sticking them to the walls or on the tables, and suggest everyone goes around and reads them.

### Facilitation Points

- It is important to stress that artistic ability is not important; they can either draw and/or cut images out from magazines.
- Explain the aim of the session and the topic area, eg growing up with HIV; experience of medical treatment; the impact of stigma when living with HIV. Comic strips will work best with simple stories which make 1 or 2 key points.

## 8. BOXES

**Estimated time:** 1 hour

**Who:** minimum 3

### Learning Objectives

- To think about how we have an external personality and an internal one and how these can be very different
- To be able to express what living with HIV can feel like internally and externally

**Materials/equipment (Handouts):** Flat pack small boxes for each member of the group, art and craft materials. If possible, a computer and printer so if they have words they want to include, they can type and print these out.

## Session Overview

This creative workshop is for young people to create a representation of themselves by using a box. Many ALHIV feel they lead a double life as most people do not know they have HIV. A box can represent many things such as

somewhere you hide things or the inside and outside together and how different they can be. This session will then produce some materials that, with the ALHIV permission, you can photograph or use in an exhibition.



© UNICEF NYHQ2001-0289/N. Toutounji

### Activity

- |   |  |
|---|--|
| 1 | <p>Explain to the group that:</p> <ul style="list-style-type: none"> <li>The box they create will represent them and enable them to express something, and deliver a 'message'.</li> <li>They can put things inside the box, decorate the outside of the box. They have free expression but need to articulate a 'message'.</li> </ul> |
| 2 | <ul style="list-style-type: none"> <li>If ALHIV want to, they can explain their box to the group. If the boxes will be put on show, it will be helpful to take notes on these explanations to present next to the boxes. Or the ALHIV who want to can write their own explanations.</li> </ul>   |

### Facilitation points:

- This is a therapeutic art exercise and so the focus is on the individual process of developing a message and self-expression, rather than on producing polished item.



- Offer some initial guidance to the group about what a box can represent (e.g. hiding things inside which cannot be seen from the outside) and get them to suggest ideas and reflect on their own experiences of keeping HIV a secret from other people.
- Do not make the box for someone, they need to do it themselves and think about the process



## 9. GAME OF LIFE

**Estimated time:** 45 mins

**Who:** 4 to 25.

### Learning Objectives

- Exploring how HIV features in everyday lives of adolescents

**Materials/equipment (Handouts):** A large dice. Question cards. 5 large numbered signs:

1.School 2.Home 3.Friendships 4. Relationships 5. Careers and work. A bag of sweets



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## Session Overview

The activity runs like a 'board game'; a participant throws a dice, they move to the sign (stuck up around the room) which corresponds with the number

thrown. At each 'numbered site' there are a pile of questions, the adolescent picks up a question, reads it out and offers a response to the scenario or question.

Activity	
1.	Person who goes first throws dice and moves to the sign of corresponding number. Picks up one of the questions and answers it. Next person throws dice and does the same.
2.	After everyone has had one turn, first person goes again this time moving around the room by throwing dice and moving that number of spaces. If there are 3 people on one site move on to the next one.
3.	If a 6 is thrown they stand in the middle of the room and give a piece of advice related to living with HIV. When they have given their advice they receive a sweet. After everyone has had a turn at a few different sites, ask everyone to sit down. Facilitator leads a final sharing session on how HIV can affect everyday life. Reflecting on responses to questions and sharing tips and experiences. Share sweets around and close session.

## Suggested questions/scenarios for exercise:

### School

1. What impact does HIV have on your experience of school?
2. If you could change one thing about your school which would make it easier for you living with HIV what would that be?
3. Your school are having a residential trip. The forms you have to complete ask you to list any health issues and whether you take medication. The school asks for all medication to be handed in to staff. How would you respond to this in relation to your HIV?

### Home

1. Does everyone in your family or the household you live in know that you have HIV? How do you feel about how knowledge of HIV is shared in your family or household?
2. Think of 3 top tips for families which would make living with HIV easier for you at home?
3. Olya is 15 and has HIV, she has two younger sisters age 8 and 10 who are HIV negative. Her parents have told her she must not tell them about her HIV? What do you think about that? What would you like to do if you were in that situation?

## Friendships

1. Have you told a friend that you have HIV? How did it go? If you haven't would you like to?
2. Think of 3 things you would most like from your friend if you told them you have HIV?
3. Alicia is 14. She has a best friend Ursula she has known since she was 6. Alicia sometimes gets quite sad and feels worried about living with HIV, there is a lot she is still confused about. She wants to tell Ursula she has HIV and that is why she sometimes feels sad. Do you think she should? What advice would you give Alicia on how to go about this?

## Relationships

1. Think of 3 reasons why telling someone you are having a relationship with that you have HIV is a good idea.
2. Think of 3 reasons you might decide not to tell someone you are having a relationship with that you have HIV. What might worry you about doing this?
3. Ruslan is 16 and has been in a relationship for 2 years. They have not had sex. He has not told his partner he has HIV. At a party one night they talk about taking their relationship further and becoming more intimate. What advice would you give Ruslan about sharing his HIV status with his partner?

## Careers and work

1. What would you like to do or be when you are older? Does having HIV affect how you think about what you want to be when you are older?
2. George is 18 and works in a barber shop. (can swap with tattoo shop). He has grown up with HIV. He decided not to tell anyone at his workplace he has HIV. One day he arrives at work and he is told he cannot work there anymore. His boss heard a rumour he has HIV and he said he is worried that he could pass HIV to one of the customers. Is this true? What do you think George should do?
3. True or false: When you start a job you have to tell your boss you have HIV?

## Facilitation Points

- If the adolescents need help to respond ask some further probing questions to help them. Try to get them to expand if they say little. If they are still really stuck and finding it difficult to talk they can ask a friend to help them with an answer. Only use this option if someone is struggling to respond them selves.
- Where there are known literacy issues, each number site could have coloured paper and the ALHIV choices a colour. These correlate with a list of questions the facilitator can read out.



## 10. LIFE MAPS

**Estimated time:** 1 hour

**Who:** 3+, but can also be used in 1-2-1 work

### Learning Objectives

- For ALHIV to undertake reflections about their lives and also consider their futures.

**Materials/equipment (Handouts):** Paper, art and craft materials



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### Session Overview

This is a therapeutic activity for adolescents to explore life experiences and consider future hopes and aims. The focus is on creating a representation of life as a journey, using the analogy of a *road* or a *river* can be helpful– something that refers to ‘movement’. The participants draw a river or road across the page, and then draw or cut out images and stick them on to represent key experiences

they have had previously in their lives, and their hopes and aspirations for the future. An opportunity to speak about their life journey should be offered to the participants, if they feel comfortable to do this.

Activity	
1	<p>Explain the activity is to create a personal life map which reflects each individual's key life experiences to date and also illustrates their future hopes. Suggest they can represent this life map as a river or road to show their journey.</p> <ul style="list-style-type: none"> <li>• Ask participants to chose at what age they want to start their map</li> <li>• Identify some important experiences they have had to date, and plot them along the map. They can draw, write, or cut out images and stick on to represent these experiences.</li> <li>• Ask participants to mark where they are now, they can consider what is significant in their lives at present.</li> <li>• Ask participants to map out some hopes and aims for the future</li> </ul>
2	<p>Give participants the opportunity to share their life map with the group and talk about it.</p>

### Facilitation points

It is important to consider your group and acknowledge that for some this may be a difficult exercise. When explaining the activity make it clear that:

- They add what they want to add
- They can start it at any point in their lives (as for some early childhood or even a time before now may be too difficult)
- When they present it they can talk about as much or little of their life map as they feel able. The facilitator can support a participant who is struggling with this to consider aspects of their life now or to focus on sharing their future hopes and aims.
- When they are making their life map, the facilitator can move around and talk to those that may seem stuck. If they seem disengaged, or find it difficult offer encouragement and support them to think about future aspirations.

## 11. WHAT PEOPLE KNOW

**Estimated time:** 20 minutes

**Who:** Small groups/pairs

### Learning Objectives

- To establish a general awareness about HIV and provide opportunities for conversations and exploration of HIV.
- To start thinking more about HIV and undertake group activities relating to it.

**Materials/equipment (Handouts):** Flip chart (large piece of paper) and coloured pens.



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## Session Overview

This is a very simple exercise that can be used as part of a number of activities. It focuses on the myths and facts about HIV

and encourages ALHIV to think about how they might respond to people who present misunderstandings about HIV.

Activity	
	Divide the group into smaller groups with a large piece of paper each
1	In one colour pen, write four things friends/people in your class might say about HIV. Go around the room and ask each group to share these
2	Now in a different colour pen, the group needs to decide what they would want to say in response to these. Go around the room and ask each group to share these and ask if anyone would like to add to this.

## Facilitation Points

- Try and keep this exercise referring to the realities of the ALHIV lives.
- Exploring the experience of living with HIV among their peer groups, who knows about their HIV? Would they like this to be different? How might they achieve this?



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## 12. SEXUAL HEALTH SESSION

**Estimated time:** 1 hour

**Who:** minimum 3, maximum 25. Single sex groups, ideally also splitting younger and older adolescents.

### Learning Objectives

- To explore issues about being HIV positive that relate to sex, sexual health and reproduction.

**Materials/equipment (Handouts)** A box, enough paper (roughly A5) for each participant, pens/pencils. Condoms and demonstrators (where none are available, use bananas or vegetables)



© UNICEF LaoPDR04802 /J. Holmes

### Session Overview

The start of this session uses the same format as 'Wishes Box', allowing participants to be able to ask confidential questions. The second part of the session is to educate the

ALHIV about condoms and make them feel confident in using them and comfortable talking about them.

**Activity**

1. Each ALHIV is given a piece of paper and pen. A box is introduced to the group and they are told this is a confidential question box.
2. Every person is asked to write something on a piece of paper. Ideally this should be a question they want answered about HIV, sex, sexual health and having a family, but if they do not have a question, they can write something else. This way no one knows who has written what.
3. Each person posts their question in the box. The facilitators then take out each piece of paper, read it out and where there is a question, ask if anyone in the group knows the answer and if they do not, the facilitator will answer it. The aim is to have discussion and debate, but also to ensure the ALHIV have the correct information.
4. After discussion, undertake a condom demonstration talking the process through with the group. Then ask them to try. Do not pressurise anyone, but make it fun so they want to join in and do not force them.  
See video: Condom demonstration

**Facilitation Points**

- It will be important to ensure clear ground rules have been established in the group and these are made clear at the beginning of the session.
- Be prepared for questions that you may find shocking and ensure no one is judged for their questions and all questions are answered.
- Keep the session fun, some of the paper may have 'rude' pictures or ask explicit questions, be prepared to use humour.
- If you do not know the answer be honest, say it is an interesting question and you will find out the answer and tell the group next time you see them.

**13. TO TELL, OR NOT TO TELL**

This activity was designed by Barnardos project in Greater Manchester that works with ALHIV

**Estimated time:** 45-60 minutes

**Who:** Minimum 3, maximum 15 (if a large group, divide into two)



## Learning Objectives

- To consider the issues of when to tell a sexual partner about your HIV status
- To explore the different barriers to telling and how to respond to these

**Materials/equipment (Handouts)** Flip chart, a pen, square stickers/post-it notes



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## Session Overview

This activity uses a narrative to support the group to talk about their fears, thoughts, feelings and experiences of talking to others about their HIV status. It is important that this session is run in a non-judgmental way and that everyone

feels they can express their feelings and how they think they would respond to each situation. There are no right or wrong answers

Activity	
1.	Take a piece of flip chart paper and make three columns. The middle column should be large and the side columns smaller. On the top of the left-hand side column write 'TELL'. On the top of the right-hand side column write 'DON'T TELL', leave the middle column blank
2.	Hand out seven stickers or post-it notes to each member of the group and ask them to write their name on every sticker/post-it.

3. There are a list of seven statements. You will write the first statement in the centre column, read it out and then ask the group '*do you tell the person your HIV status?*'. They then stick their name either in the 'TELL' or 'DON'T TELL' column next to the question, then the group discusses why they put their name in that column. Each statement is progressively more intimate and should start to challenge the group to think through what they would do.

### Suggested questions for exercise

1. You and a boy/girl meet at a party
2. You decide to go upstairs together and start kissing
3. You decide that you are going to have oral sex
4. The other person wants to have penetrative sex without a condom
5. You have penetrative sex using a condom and you have an undetectable viral load
6. You have penetrative sex using a condom but the condom splits
7. You have penetrative sex using a condom but the condom splits, but you know you have an undetectable viral load

### Facilitation Points

- How to start a conversation about HIV - so prompt them with "how would you tell at this point, what would you say?"
- Routes of transmission - where they are discussing not to tell, refer to this and different ways in which HIV can be transmitted and the various risks attached to these
- Contraception – using condoms, but also pregnancy, STIs etc
- What to do if things go wrong (condoms breaking, unprotected sex), get the group to discuss what they would do next and use this as an opportunity to educate them (if needed) on where to go for PEP/emergency contraception
- Who to go to for support if things go wrong – above are the practical responses, but also where to go to get help to talk to someone or if after telling, the person responds in a negative way.
- Understanding how medication suppresses viral loads and reduces likelihood of onward infection, promoting adherence and how, you are protecting others as well as keeping yourself well



## 14. BLIND DATE: CONDOM USE

**Estimated time:** 45-60 minutes

**Who:** minimum 4 maximum 30.

### Learning Objectives

- To encourage and raise adolescent's confidence in practicing safer sex.

### Materials/equipment (Handouts)

You will need condoms, bananas, blindfolds, a piece of equipment to record the time and a list of instructions of how to use a condom.



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### Session Overview

This activity acknowledges the fact that most sexual activity takes places at night without the lights on: the classroom with lights does not necessarily prepare adolescents for real life situations. By introducing a blindfold and making it

into a competition, practicing condom use becomes more realistic and more fun.

**Activity**

1. The competition has two stages. The first is the qualifying round: **Qualifying Round:**  
The group get into pairs. Each pair receives a new condom. One will have a model penis, or a banana, and gives the correct instructions out loud; the other has to follow the instructions as quickly as possible.
2. Each pair is timed by a judge. If mistakes are made in giving or carrying out the instructions, the pair is disqualified.
3. Second stage: **Finals:** The fastest four pairs go through to the 'finals.' These four pairs of learners are all blindfolded and timed again. Pairs can play head-to-head at the same time; the first to finish, wins.

**Facilitation Points**

- Make group rules to ensure a safe environment.
- Suggest course leader chooses partners to work together.
- Ensure everyone is in same sex partners to reduce embarrassment.
- Provide information of where the adolescents can get condoms.
- Keep it fun.

This activity was developed by Faith in People with HIV, Leicester, UK.



## 15. GIVING AND RECEIVING COMPLIMENTS

**Estimated time:** 40 minutes

**Who:** minimum 4 maximum 25.

**Learning Objectives**

- To enable adolescents to identify the positive qualities within themselves and other members of the group.

**Materials/equipment** Paper and pens.

**Session Overview**

This activity enables adolescents to experience receiving compliments and practice giving them to others. Alongside focusing on positive qualities

in others, the activity allows adolescents to build a rapport with other group members.

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Activity	
1.	Adolescents are seated in a circle. Ask each adolescent to draw around their hand on an A4 sheet and put their name on top of the sheet.
2.	Ask YP to pass their picture to other group members in a clockwise motion who will each write a positive word/s or statement they feel describes the person named on the sheet.
3.	The word can relate to what they have noticed about that person, i.e nice smile, great laugh, good knowledge.
4.	Once the hand has got back to the person whose name is on the top, the exercise has finished.
5.	Give all participants time to read the positive comments about themselves.
6.	Ask any of the members of the group if they would like to share what they have on their hand.
7.	Using the suggested questions below ask the group the following questions.

### **Suggested questions for after the exercise.**

1. How did it feel to do this exercise?
2. Was it too difficult or emotional for you? If so, why?
3. Did this exercise make you feel good?
4. Suggest that the completed hand may be taken home to put on the bedroom wall or in their home, to remind them of the good qualities they have.



### Facilitation Points

- Ensure the adolescents feel comfortable and ask them not to think too hard about their answers
- Encourage the adolescents to think about the different ways they can make a positive statement and pay another person a compliment.
- Explain that for some people they may find it hard to receive a compliment due to having low self esteem and how learning how to give and receive compliments can help to build self esteem.

This activity was developed by Faith in People with HIV, Leicester, UK.

## 16. IDENTITY SHIELD

**Estimated time:** 45 – 60 minutes

**Who:** minimum 3 maximum 25

### Learning Objectives

- Understanding each other and self-identity.

**Materials/equipment (Handouts)** Flip chart, paper, pens, pencils, crayons and blue tack for attaching sheet to wall.



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## Session Overview

This is a creative way for the group to get to know more about each other as individuals.

Activity	
1.	Hand out large sheets of paper and pens.
2.	Participants to divide their paper with pens into four sections – 4 quarters- to make a 'coat of arms' or 'shield'. First question/quarter – ask participants to write down their name, and if they know what it means. They can draw a picture to represent themselves as an individual.
3.	Second quarter –draw a picture to represent where they come from. This can include the town/country/and family or home they are from.
4.	Third quarter to draw a picture of their favorite place, where they like to visit or favorite activity they like doing.
5.	The fourth quarter is hopes for the future; this makes a 'coat of arms' or 'shield'.
6.	Ask participants to stick their 'shields' on the wall for everyone to see. Ask for volunteers to stand and present their shield to the group.

## Suggested questions for exercise:

Use questions suggested above or you can substitute or repeat exercise another time with different questions.

For example, to focus more on the experience of living with HIV:

1. How old were you when you learnt you had HIV and how did you react to this?
2. How does HIV affect your life and how do you feel about HIV now?
3. Where do you get information and support around HIV, what helps you?
4. What hopes do you have for the future?

## Facilitation Points

- Be mindful that asking adolescents to depict different aspects of their life can cause them to be reminded of difficult past experiences such as loss, bereavement etc.
- Be able to offer support as such.
- Encourage adolescents to present their shield to the group, but they need to feel comfortable to do this.

This activity was developed by Faith in People with HIV, Leicester, UK.







## 17. MY FUTURE

**Estimated time:** 45 minutes

**Who:** minimum 2-maximum 20.

### Learning Objectives

- To support adolescents with HIV to take ownership of their future.
- Identify what they would like and work out the steps to achieve this.

**Materials/equipment** Flipchart showing an example of what you would like the adolescents to do, paper, pens, felt tips and coloured pencils.

### Session Overview

This exercise promotes adolescents to feel positive and hopeful by identifying what they would like for their future. The activity will get them thinking about What they want? What they need? What could be stopping them?

Activity	
1.	Hand out an A4 piece of paper and ask all participants to draw a picture that represents themselves in the middle of the page and explain they will work on their own worksheet.
2.	Guide the group to take a three minute thinking and relaxation exercise, follow point 1 in facilitation notes below.
3.	<p>Ask participants to write the questions below around the picture of themselves. Underneath each question they will need to think about the question and write their own response:</p> <ol style="list-style-type: none"> <li>1. Do I want to study and if so what?</li> <li>2. The job or career I want?</li> <li>3. Where I want to travel to?</li> <li>4. Where do I want to live?</li> <li>5. How important is money to me and what do I need?</li> <li>6. What hobbies would I like to do?</li> <li>7. What will I be doing in five years time?</li> </ol> <p>The adolescents can work their way around the sheet using different colored felt pens, recording their ideas about their ambitions according to the prompts. They can write anything they like, words, sentences or drawing pictures. This can take anything between 10-20 minutes depending on age and attention span.</p>
3.	Give the group five minute's notice before they need to complete the activity.
4.	Facilitators can ask the group the suggested questions below (points 2-7) to encourage the adolescents further to complete the exercise.
5.	Ask the adolescents to feedback their vision for their future to the wider group.

### Facilitation Points

- For the three minute relaxation and thinking exercise- Ask the group to close their eyes and concentrate on their breathing. Use these prompts: Let your mind wander about what you would like in the future, use the questions on the worksheet to guide the group to think about, and visualize what their future could look like.
- Did you learn anything about yourself that you did not know before?
- Did you find anything difficult about this activity?
- Why is it good to have ambitions?
- What and who influences our choices? Is this a good thing?
- What do you think might help you identify or choose what you want to do in the future?
- For each question think about one step that could help you achieve your steps to the future and add these to your worksheets.



My Future	
Job / Career	
Study	Travel
5 years time	Live
Spare time	Family and friends
Spiritual life	

Adapted from the UK Youth Healthaware Toolkit and developed by Faith in People with HIV, Leicester, UK.

## 18. DRAMA ACTIVITY: MAKING A STATEMENT

**Estimated time:** 1 hour

**Who:** Each group needs 4-6 members

### Learning Objectives

- To provide an opportunity to explore information, experiences, feelings, around living with HIV.
- To use a creative process to develop a key message from this, and perform this message.

**Materials/equipment (Handouts).** Paper and pens to make notes.



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### Session Overview

This activity uses drama to help ALHIV process knowledge, experiences and feelings around living with HIV. It can be useful to use after an information activity to support them in processing the information they have just received. This activity can also be used as a presentation at a conference or event. It gives the participants creative control and can be very powerful.

Activity	
1	<p>Each group needs to decide:</p> <ul style="list-style-type: none"> <li>• <b>What</b> statement about living with HIV they want to make</li> <li>• <b>Who</b> are they making this statement to (their peers, parents/families, doctors, society, government, global community, etc.)</li> <li>• <b>How</b> they are going to make that statement (speak, song, dance, quick role play, etc.)</li> </ul>
	<p>Rules:</p> <ol style="list-style-type: none"> <li>1. They need to start and end in a 'freeze' (like a photo or 'still'). It can be the same freeze, or something different at the beginning and end. The participants should count themselves out of the 'freeze' so they all leave it at the same time.</li> <li>2. The statement must last <b>no longer</b> than 3 minutes; it can be shorter.</li> </ol>
2	Each group has the opportunity to perform their piece to the whole group.

### Facilitation points

- You may need to spend 5-10 minutes with the larger group at the beginning thinking about issues related to living with HIV.
- A handout sheet for each group which explains the task would be useful.
- Keep tight to the time limit for the performance to achieve a more dramatic effect.
- Do not take over, let the ALHIV be in control of what they do.



## 19. ANTI-STIGMA POSTER CAMPAIGN

This exercise focuses on making a poster, but the same format has been used to work with a group of ALHIV to make a short film.

**Estimated time:** 1 hour

**Who:** minimum 3

### Learning Objectives

- To gain an understanding of stigma and HIV.
- To think about ways to change people's perceptions of those living with HIV, and empower adolescents to present positive messages of change in perceptions of HIV.

Adolescents Living with HIV:

**Developing and Strengthening Care and Support Services**

**Materials/equipment:** Flip chart and pens. Examples of poster adverts. Historical and current poster campaigns about HIV and general public health campaigns. Art materials including A3 paper, pens, paints, magazines to cut out pictures from, glue, scissors.



© UNICEF NYHQ2005-0391/P. Mohan

## Session Overview

This is an art-based session where ALHIV make anti-stigma posters. This enables participants to process their understanding of HIV and related

stigma, and consider how to challenge stigma and change perceptions of HIV. The posters produced can be used in exhibitions, publications, websites etc.

Activity	
How advertising and public health campaigns work	
1	<p>Divide a piece of flip chart paper into two columns. In 1 column write; 'what works?' and in the other; 'what does not work?' Ask the group: To identify adverts from memory. What is it about them that makes them memorable? (write up what is memorable in the 'what works' column). If none of these are posters, ask if they can think of any poster campaigns by advertisers and then to say why they are memorable.</p> <p>Ask the group: To think about adverts which are promoting health and well being rather? What is about them that makes them memorable? (write up what is memorable in the 'what works' column)</p>

	<p>Show the group the examples of poster adverts and public health campaigns. Ask the group which they like and do not like and why Write up in the columns. Talk about what makes a campaign work and what does not work. Get them to think about:</p> <ul style="list-style-type: none"> <li>• Who is the campaign targeted at?</li> <li>• What is the message the campaign is trying to get across?</li> <li>• How successful is it in that?</li> <li>• How could have it been improved?</li> </ul>
	<b>Making your own campaign</b>
2	<p>Ask the group to think about what their campaign would be, answering the following questions:</p> <ul style="list-style-type: none"> <li>• What attitudes are they trying to change?</li> <li>• What message do they want to promote?</li> <li>• Who is the target audience?</li> <li>• What have they learnt about what works well and what does not?</li> <li>• How can they address the stigma related to HIV?</li> </ul>
3	Now they can either work alone or in pairs to make their own poster which aims to challenge the stigma related to HIV
4	Put the posters on display and let the group spend some time looking at them and asking for comments and responses.

### Facilitation Points

- It is important to stress that artistic ability is not important; they can either draw and/or cut images out from magazines.
- Do not make things for the ALHIV. The process is more important than the poster they produce.



## 20. REBRANDING HIV

This exercise can be used in part (running the re-branding once) alongside something to explore adherence or run as a whole session.

**Estimated time:** 1 hour

**Who:** minimum 5, maximum 25

### Learning Objectives

- To explore societal stigma and how ALHIV perceive what others think about HIV.
- To look at how ALHIV see HIV, how they stigmatise themselves.

Adolescents Living with HIV:

**Developing and Strengthening Care and Support Services**



**Materials/equipment (Handouts):** Flip chart and pens. Art material, paper, scissors, pens etc



© UNICEF NYHQ2011-0612/M. Ramoneda

### Session Overview

This session uses the concept of brands and advertising to support ALHIV to explore how they think society views

them and how they and their peers think about HIV.

Activity	
1	Ask the group to shout out what they think their HIV-negative peers think about HIV and write this up on flip chart. Do not question what they say.
2	<p><b>Rebranding HIV part one</b></p> <p>Divide the group into smaller groups and set them the task of 'Re-branding HIV'. Get them to think about advertising and brands that they like/know. They need to then think about:</p> <ul style="list-style-type: none"> <li>• Target group: adolescents their age</li> <li>• Message: what positive message can you give about HIV to make it a positive brand?</li> <li>• Slogan: something catchy, memorable</li> </ul> <p>They have 15 minutes to come up with their brand and present it to the bigger group. They can draw and write ideas. At the end the group can vote what they think is the best. Award sweets.</p>
3	Now ask the group to shout out what HIV means to them, write this up. Focus on the negatives and ask if they think other ALHIV think and feel this.

**4 Rebranding HIV part one**

Go back in to their small groups (or mix groups up if they did not work well together) and now they need to re-brand HIV for their HIV positive peers.

They need to then think about:

- Target group: ALHIV
- Message: what positive message can you give about HIV?
- Slogan: something catchy, memorable

They have 15 minutes to come up with their brand and present it to the bigger group. They can draw and write ideas. At the end the group can vote, which they think, is the best. Award sweets.

**Facilitation points**

- During these exercises get the ALHIV to consider how brands become popular and 'get a name', and then how HIV became seen as it is, where this started.
- It is important to be aware that the ALHIV's self-stigmatising may influence how they think the world sees them. Remember to challenge this, getting them to clarify what they have actually experienced and what they think they will experience.

**21. UNDERSTANDING STIGMA**

**Estimated time:** 30 minutes

**Who:** minimum 4 maximum 30

**Learning Objectives:**

- To explore what stigma is and where it comes from
- To support the ALHIV to develop resilience and coping skills

**Materials/equipment (Handouts):** List of characteristics, sweets or special stickers.

**Session Overview**

The activity uses an experiential exercise to explore what stigma is and demonstrates how particular groups can become stigmatised. Through the activity the participants experience what it is like to be excluded and treated less favorably and this experiment is reflected

upon. HIV is then introduced to enable participants to consider how stigma and HIV can occur through misinformation and prejudice. Through this they will explore stigma and HIV and build resilience and coping skills.



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### Activity

	Before the session, make a list of characteristics that are relevant for your group. This could be blond hair, brown hair, blue eyes, left-handed. For the purpose of this example, we will use left-handed.
1.	The group sits in a circle. Read out the characteristics listed one-by-one asking the ALHIV to stand up if they have one of the traits described.
2.	Once the left-handed people are standing, make them stand for a little longer and then explain that recent science has shown that people who left-handed have been shown to be a little less intelligent than others, that they often make bad decisions, that they are more likely to use drugs, not have a job and are more likely to be bad parents. You cannot see they are left-handed, so you do not know from looking at them, but these things are facts.
3.	Ask participants sitting down to respond to this, what do they think? If those standing up try to respond, say they can speak later, but for now you want to hear from those sitting.
4.	Now ask the left-handed people to go the corner of the room, make sure they can still see the rest of the group.
5.	With the remaining group bring them closer together to form a close circle and share some sweets with them, or give them each a special sticker. Ensure everyone ignores the left-handed people.
6.	Bring the left-handed people back to the larger group. Ask everyone if this activity was fair? If not why not? Ask the left-handed people how they are feeling?
7.	Debrief the group and explain this was an experiment and you were not being serious about the science research.

- |    |   |
|----|---|
| 8. | <p>Ask the group to consider how HIV is stigmatised by relating it to the previous exercise. People who are left-handed were excluded and made to feel different and less valued because the wrong information was presented about them. How does this happen with HIV?</p> <p>Ask the group: <i>What is common misinformation about HIV?</i> And write this on flip chart paper.</p> <p>Ask the group: How can they correct this misinformation?</p> <p>Introduce the group to the idea that misunderstanding is often linked to fear. Ask them to think of other examples of things that frighten people because they do not understand it. This aims to de-personalise the experience of stigma.</p> |
| 9. | <p>Optional extension activity:</p> <p>Split into small groups of about 3-4 and ask each group to think of a scenario where they have or could experience stigma in relation to HIV. Work out a drama sketch to act this out. Each group presents their drama sketch. The whole group are asked to provide feedback on each drama piece: How could the person respond to the scenario where stigma around HIV was experienced?</p>  |

### Facilitation Points

- It is important to encourage understanding about what stigma is and how it develops around particular groups of people, often linked to misinformation and misunderstanding which can lead to fear and negative judgments, creating a feeling of difference and isolation in those being stigmatised.
- Emphasis that lots of different groups of people have been stigmatised now and in the past.
- What helps? Correcting misinformation, replacing with accurate information. Recognising that this may feel very personal, but stressing it is not.
- Resilience to the effects of stigma is built when participants realise that the negative responses to HIV are down to fear and misunderstanding and it is not personal to them. They can then begin to work out how to respond in such situations.





## 22. DECISION CORNER

**Estimated time:** 45 minutes

**Who:** minimum 6, maximum 20

### Learning Objectives

- To instigate open discussion about HIV.
- To share experiences, challenge myths and misconceptions and prejudices which may exist.

**Materials/equipment (Handouts):** Signs: 'Agree', 'Disagree' and 'Maybe'. List of questions to ask the group

### Session Overview

This activity can be used with adults or adolescents. Place the three signs around the room. The group are then given a number of statements and they move around the room and stand under the sign that correlates with their answer to the statement. At this point there is a facilitated discussion and debate.

Activity	
1.	Have 'Agree', 'Disagree' and 'Maybe' in different areas of the room. Ask the group to stand in the middle and read out the first statement, asking the participants to move to the sign 'Agree', 'Disagree' or 'Maybe' depending on their answer.
2.	Ask the participants in each area to say why they are standing there. If there is no-one in either 'Agree' or 'Disagree', one of the facilitators can go there and argue for this response to encourage a lively debate.

### Questions and facilitation Points

This exercise can be used to have open conversations and discussion on areas of HIV that may touch on ethics, ideas about morality and knowledge and understanding. Questions could include:

#### 1. HIV positive women should not have children

*Discussion prompts:* prevention of mother-to-child transmission, how people can live full, long lives with HIV

## **2. You must tell anyone you want to have sex with you have HIV before you have sex with them.**

*Discussion prompts:* when to tell, how to tell, what to consider, condom use. Has anyone told before?

## **3. Parents or guardians should decide when a child is ready to be told they have HIV**

*Discussion prompts:* when different people were told in the room, what was that like? What if the child is 13 (14,15,16....) and the parent says they are not ready to be told they have HIV?

## **4. Schools should be told if one of their students has HIV?**

*Discussion prompts:* Is there is law in your country which requires this? What if children/families don't want to share information about HIV? Do you think are benefits to schools knowing?

# **23. TALKING TO OTHERS**

**Estimated time:** 1 hour

**Who:** minimum 6

## **Learning Objectives**

- To explore why people do not talk about HIV with others
- To consider when not telling is a decision made from choice and when it is a decision made from a place of fear and self-stigma
- To explore ways in which you might tell someone you are HIV positive and different possible outcomes

**Materials/equipment (Handouts):** Flip chart paper and pens. Pictures: toddler, child, teenager, adult.

## **Session Overview**

This session explores stigma and self-stigma and how these impact on people talking openly about HIV. It then uses drama, as the ALHIV explore ways to talk about HIV and consider the planning and how to manage when the outcome is not what they had wanted.





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## Activity

### Exercise one

1. Ask: *Why do people talk about things?* Write up everything ALHIV say. The aim is to see that talking is used for a number of different reasons, one being sharing as this makes us feel good.
2. Put four pictures on the wall – toddler, 10 year old, teenager, adult. Start with the toddler, who do they share things with and why? The aim is for the ALHIV to see that at different times in our lives we share different things with different people and this keeps changing.

### Exercise Two

3. Ask: *Why do some people not talk about HIV to others?* Write up their answers. At each answer, ask them to explain a little more, supporting a discussion about where people's reasons come from. Explain that some of the reasons are external (for example: work does not need to know) and others internal (for example: I am afraid they will reject me). Using two different coloured pens ask the group to say which are internal and external reasons and circle these in different colours. Finally, explain that we cannot always change the external things, but we do have control over the internal, the judgments we make about ourselves and the relationship they build with their HIV.

### Exercise Three: Role plays

4. Divide the group into smaller groups and ask them to decide on a situation where someone with HIV tells someone else they have the virus. They need to decide:
    - Who the person is who is telling
    - Who they are telling
    - Why they have decided to tell now
    - Where they decide to tell
    - A worst and best outcome that could happen

Then they plan and perform a drama to the group, first ending with the bad outcome and then the good outcome.

After each drama, the whole group reflects on: planning, getting support, useful phrases or situations (for example, face-to-face somewhere quiet rather than texting or posting on social networking).
- End the activity by summarising from the beginning:
- Why share things with others
  - How at different ages we share different things with different people
  - The internal and external reasons why people do not talk about HIV
  - Ask the group, what have you learnt about telling others? They then reflect on the outcomes of the drama activity.

### Facilitation Points

- Make sure you either write up ground rules for the group or if you already have these set, refer back to them.
- When looking at why HIV positive people do not talk openly about HIV, it is good to point out that there is a difference between someone not wanting to share something personal and someone feeling they can not share something due to fear. We all choose who we tell things to, but it is about that being a choice.
- When facilitating the discussion after each drama, ensure the group explores what negative outcomes could occur and what they would do in that situation, how they would manage this. Ensure this does not become too negative and make them feel fearful, it is about the ALHIV making informed choices. In life we do not always get the outcome we want, but that does not mean we should not do things.
- Mention that some older ALHIV who have told more people about their status have realised that they do not want people in their lives that treat them negatively because they have HIV. Most younger ALHIV may not feel that confident within themselves at this stage in their lives, but it is worth including this in discussions.



## 24. WARM-UP ACTIVITIES

All the following are activities that you can run with ALHIV to start a session or a day. These are simple activities that need the group to talk to one another to accomplish them. There are many other activities you can use, or invent your own.

1. Balloon Chair
2. Birth Line
3. Build A Tower
4. Human Bingo
5. Unbreakable Egg
6. Who's This?

### 1. BALLOON CHAIR

**Estimated time:** 15 minutes

**Who:** any size group

**Materials:** Bag of balloons for each group, cellotape. A prize.

#### Overview

Divide the group into teams. There needs to be at least two teams, but there can be more than two. They have 15 minutes to build a chair/seat with balloons and cello tape. The rules are that one of the facilitators needs to be able to sit down.

After 15 minutes, the facilitator attempts to sit on each chair. Give the winning team a prize.

### 2. BIRTH LINE

**Estimated time:** 5-10 minutes depending on group size

**Who:** minimum 10 (facilitators should be involved too)

**Materials:** None

#### Overview

This can be done with 10 people or 100 people. The whole group is tasked with forming a line in order of age, so the line starts with the oldest person in the room and ends with the youngest. This means everyone has to talk to each other to find out how old they are and then the month and possible day they were born.

You can also do this exercise with which month people are born in or trying to work

out who travelled the furthest to get to the group that day. Anything which means people have to speak to each other.

### 3. BUILD A TOWER

**Estimated time:** 15 minutes

**Who:** any size group

**Materials:** Dried spaghetti, marshmallows, cellotape, scissors, paper and anything else you can find. A prize.

#### Overview

Divide your group into teams, there needs to be at least two teams, but there can be more than two. Divide the materials equally between the teams. They have 15 minutes to build a tower using *just* the materials they have been given.

The rules are that the tower must be:

- Able to stand on it's own (so not stuck down)
- As tall as possible
- Able to withstand the breeze of waving a newspaper next to it

Give the winner a prize.

### 4. HUMAN BINGO

**Estimated time:** 10 minutes

**Who:** minimum 5

**Materials:** Design a human bingo card. This needs 12 squares and each has a picture/word illustrating something about someone and space to write a name. Examples: Has a sister; has a pet; can roll their tongue; Wears glasses; has a birthday this month. Pens/pencils. A prize.

#### Overview

Everyone has a card and must go around and ask one question to each person in the group. If they say yes, they put their name in the square. They keep going until the first person has filled up the sheet. They then shout 'Bingo' and (after checking) win a prize.

## 5. UNBREAKABLE EGG

**Estimated time:** 20/25 minutes

**Who:** any size group

**Materials:** An egg for each team, balloons, cello tape, cotton wool, paper, string, scissors and anything else you can find. You will need an outside area and a balcony or access to a window.

### Overview

Divide the group into teams. There needs to be at least two teams, but there can be more than two. The aim is to build a structure for the egg so it can be dropped from a height (window, balcony etc) and not break. Give the groups 15 minutes to design and make this and then 10 minutes to drop the structures and see which ones work.

Give prizes to the groups where their egg does not break.

## 6. WHO'S THIS?

**Estimated time:** 5-10 minutes depending on group size

**Who:** minimum 4

**Materials:** None

### Overview

Simply ask the ALHIV to find someone in the room they do not know. They then need to find out (you can write these up):

- What their name is
- How old they are
- Where they live
- Who is their favourite band/musician
- What they like to do when they are not at school/college/work
- What career they would like to have

Then each pair needs to introduce the other person to the rest of the group



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## 25. GAMES TO RUN AFTER THERAPEUTIC SESSIONS

Below are some short activities that can be run after a therapeutic or emotive activity or workshop to bring some fun energy into the group

1. **Animal noises**
2. **Changing seats**
3. **Rhythm game**

### 1. ANIMAL NOISES

**Estimated time:** 2-5 minutes

**Who:** minimum 8 participants

#### Overview

Choose three or four animals depending on the size of the group. Go around and give everyone one of the animals – duck, cow, sheep – and then ask everyone to:

- Stand up
- Close your eyes
- Make the noise of your animal and with eyes closed, go and find all the other people who are that animal by listening for and making your animal noise.

This is very silly and funny and can lift the spirits of a group after serious discussions.

## 2. CHANGING SEATS

**Estimated time:** 5-10 minutes

**Who:** minimum 6 participants

### Overview

Form a circle of chairs with one less than the number of ALHIV. Ask someone to go into the middle of the circle.

The person in the middle says, *"change seats if you are..(for example) wearing red"* Then in this example all those who are wearing red must change seats, as well as the person in the middle, so each time a new person is in the middle. Some more examples: 'Change seats if you came here by bus', 'change seats if you had breakfast this morning', 'change seats if you have jewelry on'.

## 3. RHYTHM GAME

**Estimated time:** 2-5 minutes

**Who:** any size group

### Overview

Form a circle standing. Ask an ALHIV to start a rhythm, this could be clapping, clicking fingers, using their feet, noises etc. The group follows. Then the person next to them adds a second rhythm. For example the first ALHIV starts with two claps, then the second adds 3 finger clicks, the third a foot stamp, so the rhythm is 2 claps, 3 clicks and a stamp, and so on. At the end there should be a rhythm going that everyone on the room has added too.

This can also be done with words, chants and singing.



## APPENDIX TWO: Further reading

This is not an exhaustive list, but offers some further reading or information for issues covered in this handbook. Many of the UK resources are available from the CHIVA website resource library: [www.chiva.org.uk](http://www.chiva.org.uk). For simplicity, the resources have been listed under headings.

### Attachment theory and child development

Bowlby, J. (1951). *Maternal Care and Mental Health*. World Health Organization.

Ainsworth, M., Blehar, M., Waters, E., Wall, S. (1978). *Patterns of attachment: A psychological study of the strange situation*. Hillsdale NJ: Lawrence Erlbaum Associates.

### Audits on ALHIV

Dwyer, E. (2013). *HYPNet Audit of psychological health*. HYPNet audits. BHIVA.

McDonald, S. (2011). *HYPNet adherence audit*. BHIVA.

### Harm Reduction

Hilton BA et al (2001). *Harm reduction theories and strategies for control of human immunodeficiency virus: a review of the literature*. Journal of Advanced Nursing 33 (3) 357–70).

### Residential intervention impact evaluation

Dodds, C. (2010). *Freedom To Be Summer Camp: Outcome Evaluation*. London: Sigma Research.

### Self-stigma

Ferris-France, N. (2012). *HIV and Self-Stigma Core Belief Sheet*. Open Heart House and Trinity College Dublin.

### Supporting families to talk about HIV

Supporting communication in families living with HIV:

<http://ppclondon.org.uk/supporting-communication-in-families-living-with-hiv/>

Supporting children and families in talking about HIV:

<http://ppclondon.org.uk/supporting-children-and-families-in-talking-about-hiv/>

Sharing your diagnosis with your children:

<http://ppclondon.org.uk/sharing-your-diagnosis-with-your-children/>

Communication with children:

<http://ppclondon.org.uk/communicating-with-your-child/>

## Talking to a child about their HIV diagnosis

Ely, A. (2012). *Open and Honest Practice When Working with Children*. The Children's HIV Association, UK and Ireland.

WHO (2011). *Guideline on HIV disclosure counselling for children up to 12 years of age*. World Health Organization.

### Transition to adult care

*Just Normal Young People* report:

[http://ncb.org.uk/media/496335/hiv\\_network\\_transition\\_report\\_final.pdf](http://ncb.org.uk/media/496335/hiv_network_transition_report_final.pdf)

Leaflets for young people and parent/carers:

<http://ncb.org.uk/hiv/resources-for-young-people/your-life-and-their-life-leaflets>

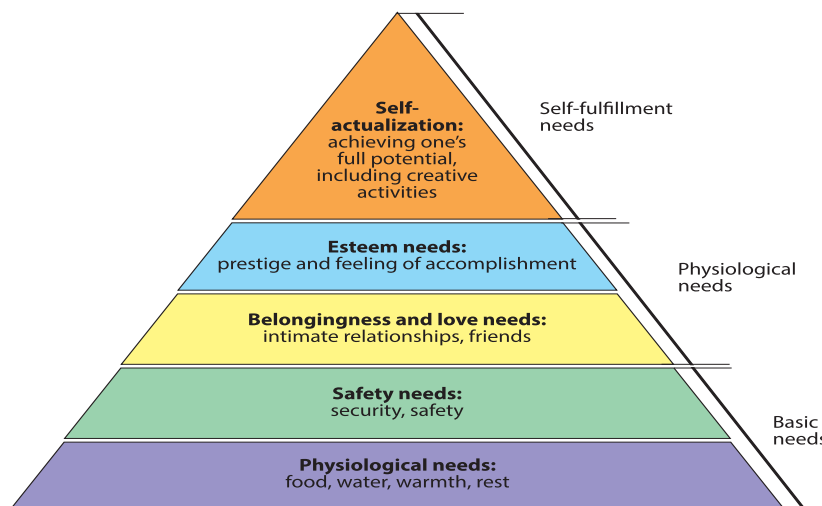
Fish, R., Judd, A., Jungmann, E., Foster, C. (2012). *Mortality amongst HIV infected young people following transition to adult care: an HIV Young Persons Network (HYPNet) audit*. BHIVA.

### Young carers and HIV

Evans, R. and Becker, S. (2009). *Children caring for parents with HIV and AIDS*. Bristol: The Policy Press

## APPENDIX THREE: Maslow's Hierarchy of Needs

**Abraham Harold Maslow** (1908–1970) was an American psychologist who was best known for creating **Maslow's hierarchy of needs**, a theory of psychological health predicated on fulfilling human needs in order of priority, starting at the base of the pyramid.



### 1. Physiological needs

Physiological needs are the physical requirements for human survival. If these requirements are not met, the human body cannot function properly and will ultimately fail. Physiological needs are thought to be the most important; they must be met first, ensuring food, shelter, warmth and clothing.

### 2. Safety needs

With physical needs relatively satisfied, the individual's safety needs then take precedence. In the absence of physical safety – due to war, natural disaster, domestic abuse/child abuse, people may experience trauma. This level of need is more likely to be found in children because they generally have a greater need to feel safe.

### 3. Love and belonging

After physiological and safety needs are fulfilled, the third level of human needs is interpersonal and involves feelings of belonging. This need is especially strong in

childhood and can override the need for safety as witnessed in children who cling to abusive parents. A lack of fulfilment within this level of Maslow's hierarchy (for example, being hospitalised or growing up in an institution, being neglected or being ostracised, etc.) can impact the individual's ability to form and maintain emotionally significant relationships in general, for example with friends.

According to Maslow, humans need to feel a sense of belonging and acceptance among their social groups. Humans need to love and be loved – sexually and non-sexually – by others. Many people become susceptible to loneliness, anxiety and clinical depression in the absence of this element of love or belonging.

#### **4. Esteem**

All humans have a need to feel respected; this includes the need to have self-esteem and self-respect. People with low self-esteem often need respect from others; they may feel the need to seek attention or glory. However, fame or glory will not help the person to build their self-esteem until they accept who they are internally. Most people have a need for stable self-respect and self-esteem.

#### **5. Self-actualisation**

'What a man can be, he must be' (Maslow, 1954). This quotation forms the basis of the perceived need for self-actualisation. This level of need refers to what a person's full potential is and the realisation of that potential. Maslow describes this level as the desire to accomplish everything that one can, to become the most that one can be. Individuals may perceive or focus on this need very specifically. For example, one individual may have the strong desire to become an ideal parent and for another, the desire may be elite athletic ability. As previously mentioned, Maslow believed that to understand this level of need, the person must not only achieve the previous needs, but master them.

## APPENDIX FOUR: Four principles of motivational interviewing

### Principle 1: Express empathy

Expressing empathy towards a person shows acceptance and increases the chance of developing a rapport with the person. It enhances self-esteem and helps facilitate change.

Reflective listening is essential to conveying empathy.

### Principle 2: Develop discrepancy

Developing discrepancy is about recognising where there is difference, here this applies to the difference in the persons present situation which may not fit with their values or what they would like to see in their future. Developing discrepancy is being able to see these differences and the person, not the worker, developing the arguments for change

Change is motivated by a perceived discrepancy between present behaviour and important personal goals and values.

### Principle 3: Roll with resistance

Rolling with resistance prevents a breakdown in communication between a person and their worker and allows the person to explore their views. The worker should avoid arguing for change and avoid directly opposing resistance.

New perspectives can be offered but not imposed on the person. The person is responsible for finding arguments for solutions.

### Principle 4: Support self-efficacy

Self-efficacy is a crucial component to facilitating change. If a person believes they have the ability to change, the likelihood of change occurring is greatly increased.

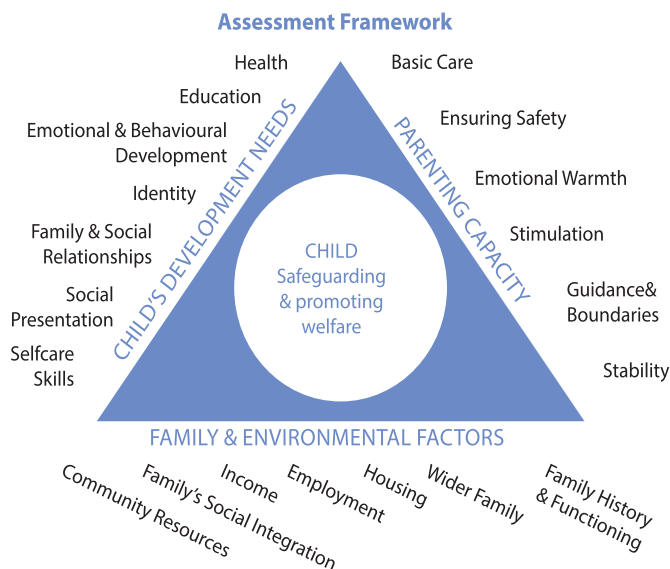
The person, and not the worker, is responsible for choosing and carrying out change.

## APPENDIX FIVE: Policy documents and practice tools

This appendix contains policy and practice tool examples:

1. A Framework for Assessing Children in Need
2. Assessment form
3. Assessment form notes
4. An example of a child protection and safeguarding policy
5. An example of a behaviour agreement
6. An example of a risk assessment form.
7. A group agreement

### 1. A Framework for Assessing Children in Need



This framework for assessing the needs of children was developed by the UK Government. (UK Department of Health, 2000)

The needs assessment framework focuses on assessing three key domains:

- The developmental needs of children
- The capacities of parents or caregivers to respond appropriately to those needs
- The impact of wider family, community and environmental factors.

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It requires some key considerations:

- The needs assessment is child-centred. Throughout the assessment, the child's perspective is at the centre and their needs are the priority.
- The need to understand children's development and what developmental milestones they should be meeting at what stage.
- Understanding that their development is affected by their experiences, whether they have a disability, and how their health is.
- Establishing a good working relationship with the child, and where appropriate their family, will be necessary.
- An assessment of needs can be seen as an ongoing process which takes place over time, not a one off event.

## 2. Assessment form

This is an example of a Needs Assessment Form used to offer 'Post Camp Support' by CHIVA when asked to provide additional support to an ALHIV who has attended the CHIVA support camp.

### A. Personal details

Name:  
DoB:  
Address:  
Phone/Email:  
Preferred way of being contacted:

### B. Your home and family

Identify household members and their relationship with the adolescent. What is home like, does it feel safe? Are you comfortable there? Who knows you are HIV positive there? Do you get on with everyone there? What about family members not living in your home?





**C. Your health**

Are you taking medication?	Yes / No
If you are struggling, who could help?	

**D. Education**

Are you at school or college? And how is that?
--

**E. The future and your dreams**

What about the future? What would you like to see happen?
---

**F. Where do you get support from**

Do you go to a service? Friends? Internet?
--

**G. Other issues**

--

Name of worker \_\_\_\_\_

Date completed \_\_\_\_\_

**3. Assessment form notes**

This above assessment tool is to be filled in with the adolescent. It is there to help map out a picture of their life at the moment and highlight their key needs. The wording has been kept simple so it can be completed with them. This document provides more detail on the intended outcome of each question.

**Question 1. Family/home life**

Gain a picture of the physical environment the adolescent is living in, mainly focusing on the people who are around and how they are all interacting with each other.

- Who does the adolescent live with?
- Identify members of the household and the relationship the adolescent has with them.

- Identify any issues to do with home, e.g., is it a secure home? Does the adolescent feel comfortable there?
- Identify whether the other members of the household know they are HIV positive. Are there any issues in relation to family relationships and knowledge of HIV?
- Are there family members who do not live in the home but are significant and having an impact on the adolescent?

### **Question 2. Health**

Explore current health issues:

- Is the adolescent taking HIV treatment medication? Are there any issues with this?
- Are there still issues relating to them being told about their HIV? Are they considering telling another person about their HIV diagnosis?
- Ask the adolescent for the name of their Doctor/Nurse and for their permission to contact them should this be needed, e.g., if they are struggling to take medication it may be helpful to make contact with their health professionals to see if any joint support would be helpful.

### **Question 3. Education**

This is to establish how the adolescent is doing in education.

- Is the adolescent currently in education?
- Are there any issues identified in relation to this?

### **Question 4. Aspirations**

- What are the adolescent's future aspirations?
- Do they need support and guidance in setting and working towards any identified goals and achievements?

### **Question 5. Social and environmental factors**

This will help you form a picture of the people who are already involved with the adolescent and how they feel about this involvement.

- Do they currently access support from other services?
- Do they appear to have a social network and access to social support through community resources, social activities, friendship groups, etc?
- Identify any social and cultural factors and any needs related to peer relationships.

### **Question 6. Other issues**

This space is to document any further issues not already covered such as general observations, emotional presentation, identified risks. Talk to the adolescent about this

area and agree with them what will be put in here. You can say things like, 'I think you seem quite sad at the moment, is it OK if I put that down?,' as well as asking them what they want included.

#### 4. An example of a child protection and safeguarding policy

##### **CHIVA Child Protection and Safeguarding Policy**

We are committed to a practice which protects children from harm. Staff and volunteers in this organisation accept and recognise our responsibilities to develop awareness of issues that cause children and adolescents harm. We will endeavour to safeguard children and adolescents by:

- Adopting child protection guidelines through a code of behaviour for staff and volunteers.
- Sharing information about child protection and good practice with children, parents, staff and volunteers.
- Sharing information about concerns with agencies who need to know, and involving parents and children appropriately.
- Following carefully the procedures for recruitment and selection of staff and volunteers.
- Providing effective management for staff and volunteers through supervision, support and training.
- We are also committed to reviewing our policy and good practice at regular intervals.

##### **Child Protection Policy**

###### **1.CODE OF BEHAVIOUR STATEMENT OF INTENT:**

- It is our policy to safeguard the welfare of all children and adolescents by protecting them from all forms of abuse including physical, emotional and sexual harm.
- This organisation is committed to creating a safe environment in which adolescents can feel comfortable and secure while engaged in any of our programmes, activities or workshops. Staff and volunteers should at all times show respect and understanding for an individual's rights, safety and welfare.

###### **2. ATTITUDES**

Staff and volunteers should be committed to:

- Treating children and adolescents with respect and dignity.
- Always listening to what a child or adolescent is saying.
- Valuing each child and adolescent.

- Recognising the unique contribution each individual can make.
- Encouraging and praising each child or adolescent.
- Staff and volunteers should endeavour to provide an example which we would wish others to follow.
- Use appropriate language with children and adolescents and challenge any inappropriate language used by an adolescent or child or an adult working with adolescents.
- Respect an adolescent's right to privacy.

### **3. ONE TO ONE CONTACT**

Staff and volunteers should:

- Not spend excessive amounts of time alone with children, away from others.
- In the event of meeting with an individual child or adolescent, make every effort to keep this meeting as open as possible.
- If privacy is needed, ensure that other staff are informed of the meeting and its location.

### **4. PHYSICAL CONTACT**

Staff and volunteers should never:

- Engage in sexually provocative or rough physical games.
- Allow or engage in inappropriate touching of any kind.
- Do things of a personal nature for a child or adolescent that they can do for themselves.

## **5. PROCEDURE FOR MANAGING DISCLOSURES AND REPORTING ALLEGATIONS OR SUSPICIONS OF CHILD ABUSE**

### **5.1 Responding to disclosures:**

- Never guarantee absolute confidentiality, as child protection will always have precedence over any other issues.
- Listen to the child, rather than question him or her directly. Offer him/her reassurance without making promises, and take what the child says seriously.
- Allow the child to speak without interruption. Accept what is said – it is not our role to investigate or question.
- Do not overreact.
- Alleviate feelings of guilt and isolation, while passing no judgement.

- Advise that you will try to offer support, but that you must pass the information on. Explain what you have to do and whom you have to tell.
- Record the discussion accurately, as soon as possible after the event. Use the child's words or explanations – do not translate into your own words, in case you have misinterpreted what the child was trying to say.
- Contact one of the child protection designated persons.
- If either designated person is not available, or it is inappropriate to approach them, the volunteer / member of staff with the concern should make direct contact with the relevant organisation themselves.
- Record any discussions or actions taken within 24 hours.
- 

## 5.2 Record

**In any case where an allegation is made, or someone has concerns about possible harm to a child, a record should be made. Details must include:**

- Name of child or adolescent.
- Is the person making the report expressing their own concerns, or passing on those of somebody else? If so, record details.
- What has prompted the concerns? Include dates and times of any specific incidents.
- Has the child or adolescent been spoken to? If so, what was said?
- Has anybody been alleged to be the abuser? If so, record details.
- Who has this been passed on to, in order that appropriate action is taken, e.g., passed to designated child protection person?
- Has anyone else been consulted? If so, record details.

## 5.3 Report this record to the designated child protection persons. These are [insert designated child protection person's name]:

- For reasons of confidentiality the only persons who need to know this information are the designated child protection persons. They will consider whether the concerns are serious and warrant a referral. Advice will be sought from specialist agencies on this. All actions will be recorded and records of reporting made.
- If the concerns relate to either of the above named persons, concerns should be taken directly to one of the three CHIVA executive officers.

Outside agencies with whom concerns should be discussed with and if necessary a referral made are [insert names of relevant outside agency name who you are required to share child protection concerns with]:

## 6. RECORD KEEPING

- All records, information and confidential notes pertaining to child protection concerns will be kept in separate files in a locked drawer or filing cabinet.
- Only the designated persons will have access to these files.

### 5. An example of a behaviour agreement

This behaviour agreement is given to every adolescent who attends the CHIVA support camp. They are required to sign it, and it is referred to during camp when needed.

## BEHAVIOURAL AGREEMENT

To keep everyone safe, physically and emotionally, we are asking each adolescent who is coming to the camp to sign this agreement. Breaking this agreement could end in you being sent home.

- Alcohol at the residential is absolutely forbidden.
- Anti-social behaviour, which includes bullying, racism, sexism and homophobia will not be tolerated. Teasing because people's accents are different or because you come from different parts of the country or the world is not acceptable.
- The use or possession of illegal drugs is completely unacceptable and may result in the involvement of the police.
- If you have to smoke, you must only smoke in the designated smoking area, not in the bedrooms or other buildings.
- The venue will have its own rules that will be about keeping you and everyone else safe. We expect you to keep these rules.
- At night-time, everyone must be back in their house by 10pm and in their bedrooms with lights out at 11pm. If this happens, then we will relax this rule on the final night.

We expect *everyone (this includes all workers)* to:

1. Be kind and polite to others.
2. Not shout or swear at others.
3. Treat the venue equipment and other people's belongings with care and respect.
4. Take part in the activities provided.
5. Not cause danger to anyone including to himself or herself.
6. Not hit/kick/bite/scratch anyone else.
7. Not leave the group without telling a key worker.

8. Not resort to any form of bullying such as:

- **Physical:** hitting, kicking, taking belongings
- **Verbal:** name-calling, insults
- **Indirect/emotional:** spreading nasty stories, excluding from groups.

### **Discipline Steps**

We will always give you the chance to explain your behaviour and where we can, we hope to sort this out without giving you a warning.

We have a three-step warning system:

#### **Step One**

First warning: this will be a verbal warning from your key worker.

#### **Step Two**

Second warning: this will be another verbal warning, but this time from your key worker's supervisor.

#### **Step Three**

Third warning: this will come from the camp manager and will include a telephone call home. If you receive a third warning that will mean that you may be sent home.

Under severe circumstances you could be sent home immediately.

By signing this form I agree to the rules set out here.

Name:

Signature:

Date:

## 6. An example of a risk assessment form

Area of Risk	Level of Risk	Description of Risk	Action taken and by whom, information gained	Management of risk

### Outcome of risk assessment:



## 7. An example of a group agreement.

**Purpose:** To establish an agreed-upon code of behaviour for the group so that each participant feels safe and able to rely on others in the group.

**Respect others as individuals** - giving the other person our undivided attention (not being on the phone etc.), listening politely and not ridiculing what other people say, one person talking at one time.

**Respect other's culture, race and background** - realising that we are all different and respecting everyone unique culture, race and background.

**Take turns**- let everyone have a turn.

**Confidentiality** – What is said in the room stays in the room.

**Winning is not the only goal** - understand that whilst winning is one goal - trying your best and shared teamwork matter too.

**Speak openly** – but kindly and speak how you would like to be spoken to.

**Have the right to say “no”** - if we don't want to take part in a specific activity, that's our right, but we also appreciate that trying something new or different is helpful and can be fun.

**Have fun and work to the best of our ability** and try as hard as we can.

**Respect other people's possessions** - don't damage other people's things or take anyone else's property without asking.

*This group agreement was developed by Faith in People with HIV, Leicester, UK*

