

Developing support services for children, young people and families living with HIV

A handbook for service providers

Magda Conway



National Children's Bureau

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- ◆ undertake high quality research and work from an evidence-based perspective
- ◆ disseminate information to all those working with children and young people, and to children and young people themselves.

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Foreword

This is an inspiring publication born out of a depth of experience and genuine concern for the welfare of children, young people and families living with HIV.

It is full of highly practical examples of what works in helping to overcome the many challenges faced by affected and infected individuals. It contains comprehensive contact details for organisations that have experience and can help anyone setting up new services. The text is continuously brought to life by quotes from young people and family members, which anchor this handbook in reality. There is a very helpful section at the end that identifies current potential sources of funding.

On behalf of the Children's HIV Association of the UK and Ireland, I congratulate Magda Conway and her contributors and hope that this document will act as a stepping stone towards the launch of innovative and constructive initiatives to support children, young people and families living with HIV.

Gareth Tudor-Williams
Chairman, CHIVA

Introduction

I am a normal boy who does everything my age group does. I listen to music and play football; I've got a girlfriend and I go to college. But I have HIV and that makes me special. (Matthew, aged 14, HIV+, in CWAC 2004)

At the time of producing this resource, there were more than 1,000 under-19s known to be infected with HIV living in the UK. The number of affected children, defined as those living in a family where one or more member is HIV infected, is unknown. Over the last decade, the number of women infected with the virus has quadrupled leading us to estimate that there are at least 15,000–20,000 children affected by HIV in the UK.

TERMINOLOGY

Infected relates to a child or adult who has HIV.

Affected relates to a child or adult who lives in a family where one or more members are infected with HIV.

Child is used to represent children between the ages of 0 and 10.

Young person is used to represent those aged between 11 and 19 years old. (Many organisations are extending their services to those in the 19–25 age group. Much of the following can relate to their needs and this age group may need to be considered when developing services.)

Organisation is used to represent any charitable or statutory body offering or developing services.

Parent/carer is used to represent anyone with parental responsibility for a child, so includes carers, foster parents and step-parents.

Staff is used to represent both paid and unpaid employees of aforementioned organisations.

Who is the handbook for?

This resource has been designed to offer information, guidance and support to anyone who has an interest in developing, or already runs, support services for children and young people infected with or affected by HIV. The information will be of use to voluntary and community sector organisations and the statutory sector including social workers, health professionals and youth workers.

It was developed through three national consultations with statutory, voluntary and health sector professionals held in London, Birmingham and Leeds at the beginning of 2005. A wealth of information and ideas was gathered, which has influenced the format and content of this resource. Both infected and affected young people have also been involved through consultation events allowing their perspectives to be included.

How can it be used?

This resource can be used as a planning tool to assist organisations and individuals in planning, developing and maintaining work with infected and affected children, young people and their families. Where possible, this should be in the context of partnerships with statutory services, including health and social care. It can also be used as an evaluation resource for organisations and individuals already working with these groups to review their practice.

Children, young people and parents/carers living with HIV are first and foremost people. They have the same variety of complex personalities, lifestyles, opinions and experiences as everyone else. What they share is either being infected with or affected by a highly stigmatised chronic illness.

All people will see is the HIV if I told them my diagnosis. I want to be known as Barbara first. (Barbara, HIV infected, aged 16)

As HIV-infected people live longer, healthier lives, new concerns are emerging for this group, which include the effects of HIV on development, the long-term effects of medications, an increase in disabilities, learning and school-based problems, adherence to medication, body image and depression in adolescents. All of these factors can impact hugely on their well-being. There will potentially be many professionals involved in that child's life, from health, child care, education, social services and the voluntary sector.

Section 1 offers an overview of statutory requirements and good practice guidance for organisations, and includes good practice in relation to staff working practices. It explores some of the issues that may affect staff working with this client group and ways in which organisations can support them.

Section 2 explores the needs of parents/carers living with HIV in relation to supporting their children. It contains information and practice examples on specific parenting issues and suggests ways to support parents/carers.

Section 3 focuses on young people, some of the issues they face living with HIV in the UK and examples of ways to support them through both individual support and within their peer group. It also includes a number of practice examples.

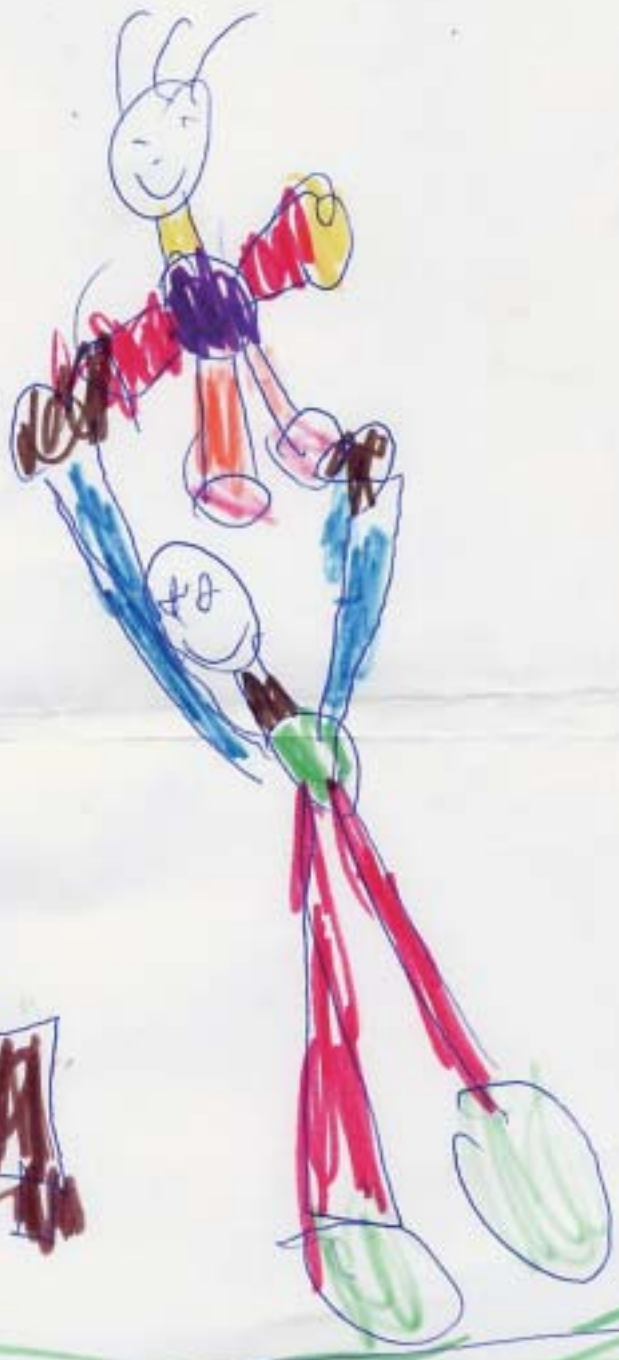
Section 4 explores issues for children infected and affected by HIV. Some are similar to those of young people and others are specific to this age group. This is followed by examples of support that can be offered to this group, both as individuals and through group work.

Section 5 offers support for fundraising, including key points to consider, resources which may be of use and a list of possible trusts that may consider funding this work.

Finally, the annexes offer a coherent list of resources, tools, activities and publications, as well as contact details of where to acquire useful information.

This is not a definitive guide. Infected and affected young people are a marginalised group who at present have very little direct emotional support services available to them. This handbook aims to demystify working with this group and to support organisations in either initiating the development of this work or being proactive in including this group in work they undertake.

If my mum had cancer I'd be able to tell my friends about it and they'd be sympathetic, but because she has HIV I can't because I don't know how they would react. (Affected child, in Health Through Action 2003)



What makes HIV different is the way you get it. Other illnesses are much worse, but people just link it to sex and that's what makes it different.
(Affected young person, Karibu 2004)

A variety of organisations are working with children and young people infected with and affected by HIV. Some may already work with families; others may already work with children and young people, but not explicitly providing child-centred support for children infected with and affected by HIV.

Organisations will have many policies and procedures in place. This section offers an overview of statutory requirements and good practice guidance for organisations; it includes good practice in relation to staff and their working practice. It also explores some of the issues that may affect staff working with this client group and ways in which organisations can support them.

Good practice dictates that all policy and procedure is regularly audited and evaluated to ensure it is achieving its aims and being actively promoted and upheld throughout the organisation.

Statutory requirements

The following are generic policies that an organisation must have in place. Some are specifically about working with minors, and others may need to be reviewed to ensure they cover minors:

- ◆ child protection
- ◆ health and safety
- ◆ equal opportunities.

Child protection

A child protection policy must state what staff need to do to plan ahead to minimise risks of possible abuse occurring, and give guidance on what should be done if a situation or disclosure about abuse does occur. It needs to outline the definitions and signs of abuse; procedures for reporting and accountability within an organisation; promote a culture of openness where people are encouraged to share concerns; and explain how it will link in with local statutory agencies such as the Local Children's Safeguarding Boards (LCSB).

Employees are duty-bound to report child protection concerns to the police or social services and in this instance confidentiality can be breached. The LCSB can

assist organisations in developing a policy. All staff should undertake training in child protection and LCSBs can support organisations in locating this.

A child protection policy must include the following:

- ◆ All staff working directly with minors must be Criminal Records Bureau (CRB)-checked prior to having sole responsibility for a child or children.
- ◆ A risk assessment process must be carried out when doing direct work with children and young people. This should cover the building where the organisation is based and, if undertaking trips, it should cover transporting minors and providing transport for minors. These procedures should include a checklist/form for staff to complete and adhere to.
- ◆ The adult-to-child ratio must be worked out to ensure that there is always adequate supervision; for instance, if a staff member falls ill during a trip, there must be an adequate number of staff left to ensure the children's safety.
- ◆ There must be clear guidelines and a referral process for staff who have any concerns about a child's welfare or safety. A designated staff member(s) should be located within the organisation who is the key liaison person in the event of any child protection concerns or issues that need to be addressed.

Health and safety

Organisations may wish to draw up a separate child health and safety policy, although reviewing the organisation's generic policy and ensuring that it covers minors, and possible additional health and safety issues that working with them may raise, may be sufficient.

All crèche facilities and provision will be subject to local authority inspection and the environment will need to conform to particular standards. The Office for Standards in Education (Ofsted) can provide advice in this area via their website (<http://www.ofsted.gov.uk/>).

Equal opportunities

An equal opportunities policy clearly states what is unacceptable in the organisation with regard to exclusion on the grounds of race, ethnicity, gender, age, disability and sexuality. The policy should also state how an organisation will proactively seek to encourage all members of the community to access services and resources (unless particularly targeting a certain group) and what kind of diversity of service can be delivered.

At present there is a great diversity in the ethnic and cultural mix of families living with HIV, with African communities disproportionately affected.

Organisations and groups need to celebrate and support such diversity within the context of ensuring that all children are treated equally within all policies and working practice.

An equal opportunities policy can also be a starting point for 'rules' for young people's groups, stating, for example, that no oppressive language or actions are permitted, and that bullying of any kind is unacceptable. It also needs to state how the organisation will act on complaints or incidents that conflict with this policy, and have a clear complaints procedure for both staff and service users.

*Before, I was very alone. I had no one to talk to and I felt my life was going to end. I'm getting more confident and I'm beginning to learn to cope.
(Alice, aged 16, HIV+, in Body & Soul 1998)*

Good practice guidance

HIV within a family can present complex issues for organisations. Having clear statements and policies on the organisation's stance on these can empower both those working for the organisation and those accessing services. The principal issues are:

- ◆ disclosure
- ◆ confidentiality
- ◆ medication
- ◆ transport
- ◆ drugs and alcohol
- ◆ codes of conduct
- ◆ child-centred practice
- ◆ registration and parental consent
- ◆ declaration of health.

Disclosure

A policy for disclosure offers the opportunity to clarify to staff, service users and others, exactly what the organisational position is on this issue. It can state what the organisation can offer its workers, in the form of training and support; what it can offer to parents/carers if they seek support on this issue, and what it can offer children and young people once they are aware that they are living with HIV. This can further be explored in staff guidelines and work undertaken throughout the organisation.

Some organisations may choose to state in a disclosure policy that, once young people have reached a certain age, the organisation can only offer services to those who are aware of HIV in their family, thereby ensuring that there is consistency, clarity and integrity in working relationships formed with young

people. Within this context, preparation for disclosure can be a specific service offered to families.

Present practice promotes the idea that disclosure should not occur as a one-off event. For the infected child, the partnership developed between the parent/carer and all the professionals involved in that child's care should guide this process. For both infected and affected children, the parent/carer may request support from other voluntary or community-based organisations.

Confidentiality

Confidentiality in this context relates to maintaining privacy of information about service users, whether this is medical information or information about their current situation. When providing services for anyone infected with or affected by HIV, confidentiality in regard to information about their illness is paramount. A policy statement on this topic will clarify staff boundaries and what service users can expect in terms of how information regarding them is kept within the organisation. For example, the organisation acknowledges the importance of confidentiality for its service users. Therefore, unless there is cause for concern in relation to the service user endangering themselves or others, or issues that relate to the organisation's child protection policy, they will not pass on information about service users without first gaining their permission.

This is extremely important for families and young people accessing non-HIV services, such as generic youth services or carer support groups. Such organisations may want to seek further information about policy and protocol when working with infected and affected young people, many of which are explored in *HIV in Schools* (NCB 2005).

Medication

If a member of staff of an organisation is taking a child or young person on an outing or a residential break and the child is taking regular medication, whether this is HIV/AIDS-related or not, there needs to be a policy that advises staff and parents/carers on whether the organisation or individuals in it can take responsibility for this, and if so, the process that needs to take place prior to this. Again confidentiality needs to be considered here.

The Department for Education and Skills (DfES 2005) has produced guidance for *Managing Medicines in Schools and Early Years Settings*. This may be a useful reference when developing policy and protocols; it presents issues such as administering medication, storage, record keeping and developing protocols with parents/carers and their children.

Transport

This policy will contain different elements, depending on the service users and what services are offered, and may be covered in the child protection policy. Points to consider are whether staff are expected to transport children in their personal vehicles and the implications of this for their insurance policies. Another point to consider is the staff–child ratio when transporting children, and the implications if the staff member is the driver. Risk assessments should be completed prior to transporting children.

Drugs and alcohol

This policy can be either specifically directed at ‘minors’ or it can be a generic organisational policy. If it is generic, it may be better to separate illegal drugs and alcohol, and define at what times it is acceptable to have alcohol on the premises (i.e. for celebrations).

An example of this could be to state that the organisation upholds the law and therefore minors may not bring alcohol to, or drink alcohol on, the organisation’s premises or at events organised by it. Similarly, bringing any illegal substances, either to the premises or an external event, or using them in these contexts, is completely unacceptable, and the police will be immediately informed if anyone is found doing so.

Codes of conduct

Building appropriate and supportive relationships while maintaining professional boundaries is paramount when working with any child. This is even more important when supporting children with a life-threatening illness, or those who are vulnerable due to their parent’s/carer’s ill health. Staff may need guidance with regard to offering support to the children, equipping them with the skills they need to thrive, rather than developing dependent relationships with specific staff members. This highlights the need for regular supervision of staff and debriefs after group meetings, to reflect on the service and allow staff to offload their feelings and responses to the work. A policy statement on what constitutes acceptable professional boundaries and codes of conduct helps to clarify this for all staff and service users.

Intense relationships in which both staff and child become in some way co-dependent are damaging to all involved. All children need to feel valued and cared for. Services need to strive to empower children and equip them with the

life skills to build their own support networks. Staff provide a service, and within this service they can support children, but children need to be able to find support elsewhere when the service is not available. Good codes of conduct help to foster self-control, self-reliance, kindness, cooperation, curiosity and motivation. Without good working relationships children will not necessarily listen to or trust workers, and may ignore their opinions, however well intentioned.

Child-centred practice

Child-centred practice when working with minors can be time consuming and involve hard work, both physically and mentally. It may mean sacrificing what staff wish to do at work for what a child needs to do. Building services around the needs of children and young people, and empowering them to drive these and their content, will ensure that the service meets their needs (see Practice example 1).

Registration and parental consent

When staff are working separately with children or young people under the age of 16, a registration/parental consent form (*in loco parentis*) should be completed so staff have access to contact numbers for the parent/carer and so that, in the case of an emergency, staff can take parental responsibility. This documentation should include the name and contact number of the doctor/consultant if applicable; consent to administer medication (if agreed under medication guidelines); and access to emergency health treatment if needed. The form should include full facts about what activities young people are expected to take part in, and will allow for some parents/carers to give partial consent for certain activities and exclude any they feel their young person should not undertake for particular reasons. This will encourage parents/carers, who may initially have considered preventing their child from attending due to their concerns over particular activities, to allow their child to participate.

Declaration of health

Children and young people infected with HIV have compromised immune systems. This needs to be considered by all those coming into contact with this group. For example, if a group of children are being taken away on a residential break, all staff should complete a 'Health Questionnaire' a few days prior to departure. This can ask a list of simple questions such as:

- ◆ Have you ever been colonised/infected with MRSA?
- ◆ Have you been in contact with any infectious disease within the last three weeks, e.g. chickenpox, measles, mumps, TB?
- ◆ Have you previously had chickenpox, and are therefore immune?
- ◆ Are you unwell at the present time, e.g. you are suffering from diarrhoea and /or vomiting? (Great Ormond Street NHS Trust n.d.).

This will be a positive step towards limiting the possibility of children with compromised immune systems being exposed to diseases that may pose a health threat.

I want people to know that they can't catch HIV just by touching us. (HIV+ child, in Health Through Action 2003)

PRACTICE EXAMPLE 1: CHILDREN WITH AIDS CHARITY (CWAC)

Child-centred practice and individual learning plans

Children With AIDS Charity (CWAC) runs an education programme on its premises for HIV-infected young people. Each young person completes a personal profile form, which includes a list of learning needs. This is talked through with the facilitator and drawn up into an individual learning programme. Ongoing reviews are undertaken, all led by the young person and prompted through the facilitator asking questions. The review serves to clarify the needs of the young person and monitor how they feel about the process/project work so far.

All staff are encouraged to work with each young person in order to promote team working (because there will be individual strengths and weaknesses within the staff team) and to encourage the young person to take responsibility for developing different working relationships.

This pilot project developed through demand from HIV-infected young people who clearly found making the transition from child to adult services difficult. They came with a range of issues, including difficulty coping at college; being excluded from school; and not feeling employable. Due to restrictions on funding and space, the project is being kept low key at present, but CWAC hopes to promote this aspect of supporting HIV-infected young people throughout both the HIV sector and the children and young people's HIV sector.

I never thought it possible that someone in my position could achieve what I have done in the past year. (HIV-infected young person)

Children With AIDS Charity is a national charity with the simple aim of working towards a future without prejudice for these children and their families. For further information or to view their publications and resources visit <http://www.cwac.org/> or telephone: 020 7247 9115.

Issues for staff

Equipping staff with skills, information and guidance will enable them to develop appropriate relationships with children, young people and parents/carers. It will also support the development of user-centred services that meet the varying needs of those targeted and work towards high quality service provision throughout the organisation:

- ◆ HIV awareness
- ◆ cultural diversity
- ◆ talking and not talking about HIV
- ◆ supervision and peer support.

HIV awareness

It is paramount that all staff working directly with infected and affected children and young people should maintain a certain level of knowledge on the topic. Children ask questions and staff need to be prepared either to answer these directly or to find out the correct answers.

Organisations would be well advised to build links with their local HIV health professionals. This may be a paediatric multi-disciplinary team or, in areas of low HIV prevalence, the adult team or GUM (gynaecological and urinary medicine) and sexual health clinic staff. This can act as an information-sharing route and a possible link to access training. Links with paediatric HIV services are also strongly recommended, although this may mean linking with specialist centres in London if there are no local or regional services available (see Contacts for London centres, page 15).

Cultural diversity

A disproportionate number of families living with HIV come from African communities. Staff need to appreciate cultural diversity, and different value bases and belief systems in their working practice. The term 'African communities' includes over 50 countries and a variety of languages, religions, values and belief systems. Acknowledgement needs to be given to how these inform perceptions of the child and family relationships, and how they can influence the role and expectations of a child. Staff should have the opportunity to explore this, and what it means for working practice and for developing relationships with both parents/carers and children.

It can be helpful when working towards ensuring an inclusive atmosphere where all feel welcome, to have a 'ground rule' that English is the spoken language during group meetings (although there may be situations when this would not be appropriate).

CONTACTS FOR LONDON CENTRES

Great Ormond Street Hospital for Children NHS Trust (GOSH)

Contact: Margaret Clapson and Jacquie Flynn (clinical nurse specialists)

Email: clapsm@gosh.nhs.uk / flynnj@gosh.nhs.uk

Telephone: 020 7813 8231

St Georges NHS Trust (Tooting)

Contact: Sheila Donaghy and Sharon Story (clinical nurse specialists)

Email: Sheila.Donaghy@stgeorges.nhs.uk / Sharon.Storey@stgeorges.nhs.uk

Telephone (switchboard): 020 8672 1255

St Mary's Hospital (Paddington)

Contact: Jo Dodge, family clinic coordinator

Email: familyclinic@st-marys.nhs.uk

Telephone: 020 7886 6349

Talking and not talking about HIV

Talking about HIV or not talking about it can raise a number of issues for staff members, and guidelines or protocols can give staff clarity and confidence when working with children. The two main areas that can concern staff are secrets and the child asking them direct questions.

'Secrets'

Staff may feel the burden of knowing a child's HIV status when the child is unaware, and worry about how that child may react towards them, and whether the child may resent this, when they are eventually told. Protocols, internal training and staff peer support can clarify and reassure staff as to the role they can play in supporting both the parent/carer and/or child, and encourage them to maintain professional boundaries.

'What if the child asks?'

There should be clarity on the question of what staff tell a child if they ask outright questions. Overtly lying to a child could permanently damage relationships between staff and children, so it may be that the organisation establishes guidelines for staff and that parents/carers accessing the service are made aware that if a direct question is asked, staff will not lie. Giving staff the

opportunity to explore this scenario through peer sessions, where alternative answers can be practised and thought given to what should happen next in relation to the parent/carer and the child, would be beneficial.

Supervision and peer support

Although it is normal practice for staff to receive formal supervision, the potential impact that working with chronically ill children may have on individuals must be acknowledged. Therefore organising additional supervision, whether it be external 'therapeutic' support or in the form of peer support, is well worth considering. Linking with healthcare professionals, especially psychologists in this field, can be extremely helpful, for example in helping set up or facilitate therapeutic supervision sessions run by external practitioners.

I don't feel isolated all the time, but when some friends talk about HIV/AIDS they have this perception from the media. I am scared to reply to them because most people believe what is written in the papers even if they know it's not true. (Young person, HIV+, in CWAC 2004)

PRACTICE EXAMPLE 2: CHILDREN AND YOUNG PEOPLE HIV NETWORK

Disclosure session for staff team

The Children and Young People HIV Network was invited to run a session at Positive Partners/Positively Children with family support staff. The session aimed to explore issues faced by parents/carers living with HIV, to clarify some of the issues families face with regard to talking about HIV and to explore ways to support families through the process of disclosure.

The session looked at the barriers for parents/carers when talking to their children and how to support parents/carers through these. It then focused on the role of the staff and their professional boundaries. Role-play was used to explore the issue of building significant relationships with children when staff know they are infected with or affected by HIV, carrying this burden, and how they may react when the children find out.

The whole session was interesting. The scenarios looked real and very useful for the purpose.

Children and Young People HIV Network is based at the National Children's Bureau and works nationally to promote the voice of children and young people living with HIV in the UK in policy and practice development. For further information visit www.ncb.org.uk/hiv



2 Supporting parents / carers

Duncan

Charlotte

12/9/15

Clairmaire

2 Supporting parents/carers

For me the most important thing I've learnt is: live a happy life while it lasts. I've managed that from the love of my mother. (Matthew, aged 14, HIV+, in CWAC 2004)

Many organisations developing work with infected and affected children and young people will be doing this within the context of family work. Thus including the parents/carers in the development of services and exploring their needs as parents/carers is essential. Involving parents/carers will support the development of appropriate services to meet their needs as parents/carers, and also ensure their support and understanding of the children's services being developed. It will also help parents/carers to trust the organisation and they will be more likely to consent to their child attending groups.

This section explores key needs located through research and consultation with children, parents/carers and practitioners with regard to being a parent/carer living with HIV. Specific parenting issues and suggestions as to how to support parents/carers through these are presented, all within the context of the child's well-being.

Issues faced by parents/carers

Of course I want her to learn to do things, but I want her to learn not because I'm ill, but because she's learning as a child. When it comes to this, where she does these things because I'm ill, not because she's learning, when it comes to when she has to do it because she feels Mummy's not able to, well that's not right. I hate it. (HIV+ mother, in Lewis 2001)

Parents/carers may present a variety of issues and these will vary between individuals and families. Many factors can impact on a family's situation and some of these will not be linked to living with HIV. What follows discusses some of the issues parents/carers look for support within relation to parenting in the context of living with HIV.

Should I tell my child?

For many parents/carers, talking about HIV, whether it is their own diagnosis or their child's, is a complex issue and they may need extensive and long-term support with it. For some, there will never be a right time; their condition will be part of a personal journey that they do not want to share. But many parents/carers do seek support with this issue, from either their children's or their own health professionals, or their peers and organisations that they access.

Areas that parents/carers can struggle with include seeing the information as a burden on their child, or fearing that their child will break confidentiality. Working with parents/carers to support them through these dilemmas and clarify their thinking is beneficial and can be done both with individuals and in peer groups.

I need professional help. I need more help than we can explain. I can't tell her just like that; it has to be slowly, with help. (HIV+ mother, in Lewis 2001)

Fear and understanding

For the HIV-infected parent/carer, fear of how the child will react – whether they will be angry, upset, violent or reject the parent/carer – can be a huge burden. Other fears can include fear about the future, whether the parent/carer will be there to see the child grow up, or fear of the child's own possible death. In addition to these fears are worries about what the child will do with the information once they are told, whom they will tell and the implications this has for the family. Sharing these fears and hearing about the experiences of other parents/carers can help alleviate these fears and help them move on from them.

Questions that may arise from talking about HIV

When a parent/carer talks about HIV it is not in the abstract. It will be about them and personal details about their lives that, under other circumstances, they might not choose to discuss with their child. The questions 'How did I get it and how did you get it?' may arise. For some cultures, talking about sex and sexual health is a major taboo, or is generally undertaken by someone other than the parent/carer.

Preparing parents/carers for questions that may arise through providing information, education, role-play, and having the opportunity to work through fears and concerns in peer group support sessions can increase their confidence. Practice experience has shown that when parents/carers have spent time discussing other personal issues with young people, such as sexual health, and a good communication habit has been built up, the task of talking about HIV can be easier. In addition, parents/carers may not feel well enough equipped to talk about the virus and all its implications without preparation and support.

My mum is positive and my uncle. My dad died of HIV. I found out when I was 11 years old. At first I acted like I didn't care and now I just want to be there for her. I don't want to hurt her. We don't talk about it, it's not even mentioned – like I don't even know. (15-year-old, in Positive Vibes 2004)

Stigma

Stigma is not specific to parents/carers and affects all HIV-infected and affected people. The stigma and discrimination parents/carers experience, whether it be through first-hand experience, or through the way in which society or the community relates to HIV, influences self-esteem, parental attitudes and their willingness to talk with their children. Many fear negative moral judgements from family, friends and community.

Guilt and blame

Guilt and blame may arise in relation to the parent/carer passing the virus on to their child, and the implications this has for the relationship. These feelings may occur if the parent/carer feels that, because of ill health or drugs toxicity, they are not performing their parental duties, or in relation to how their possible death will impact upon their children. Again, sharing this with other parents/carers, developing coping mechanisms for periods of ill health and acceptance that they are doing the best they can, are all beneficial to both adults and children.

Supporting parents/carers

Who is going to help me? Sometimes [my son] has to stay away from school, even three days off school at a time. Last [term] there was so many times when he wasn't able to go to school. I tell them I am sick – I say, 'Look, my children don't go to school because I can't take them. Help me.' (HIV+ mother, in Lewis 2001)

This section offers practical ways to support parents/carers in dispelling some fears, sharing experiences and supporting their children. As HIV disproportionately affects African community groups, parents'/carers' expectations through their own experiences of growing up in a different culture may conflict with their children's expectations. This may mean they need support with their understanding of what it is like for children growing up in the UK.

Support is divided into two categories: *individual support*, and *group or peer support*. Each individual may prefer one to the other or find both equally useful.

Consultation

Consulting with service users is essential in developing needs-based services. When developing any service or group, parents/carers need to be involved from the beginning. This will mean that the service developed meets their needs and is well used as those accessing it have a sense of ownership. This process will also ensure the most appropriate service is developed, whether this is included in the following examples or not.

Individual support in relation to being a parent/carer

I'm not afraid because my mum talked me through it. (12-year-old, in Positive Vibes 2004)

Individual support can range from informal conversations with a worker, to services that offer assistance and emotional support specifically on and around parenting in the context of living with HIV. Some services may provide family support work, through which the parent/carer can access parenting support, respite opportunities and the opportunity to discuss other issues that relate to living with HIV as a parent/carer. These could include how to talk to their children about a number of issues, including educating them about HIV. For parents and carers, having the opportunity to discuss the barriers that they face, express their fears and concerns, and explore possible solutions can be invaluable.

PRACTICE EXAMPLE 3: HEALTH THROUGH ACTION

Support for parents/carers

Health Through Action is a Barnardo's project that supports children and young people living with HIV. Part of this work involves supporting parents/carers who have multiple and complex needs, which can include asylum issues, poor housing, lack of finance, isolation, as well as the stress of living with HIV.

Although the service is there to support children and young people, relationships are developed with parents/carers to support them in accessing local generic children's services within their community, such as Sure Start, assisting and building on their own networks of support and giving practical and financial support as this all has a positive impact on the child and on the life of the family.

Developing relationships is essential to working in partnership with parents/carers. It can support parents/carers in unravelling their own experiences, giving them time to explore their own feelings of anxiety or parental guilt. It ensures that they have a good, current knowledge and understanding of HIV that also takes account of the cultural and religious aspects of their lives. This then enables the parents/carers to have more confidence when sharing HIV information with their child and enables that child to obtain consistent messages from all involved in their care.

As a parent I knew I didn't have the answers my teenager needed, I also knew he needed a friend to trust and confide his emotions in and in Barnardo's all those questions are answered. (Parent)

Barnardo's **Health Through Action** is a charity based in Manchester. The project has a team of specialist social workers, family support staff and volunteers that offer support services for children, young people and their parents/carers living with HIV. For further information contact the project on 0161 273 2901.

Group or peer support

Groups can take many forms and many organisations already run groups for HIV positive women and/or men. This section offers some possible examples of how groups can specifically explore the issue of being a parent/carer and living with HIV.

Workshop on talking to children about HIV

This could be run as part of an already established peer support group and be a one-off session led either by young people or by parents/carers who have been through this and can share their experiences with the group, facilitate discussion and answer questions. The workshop could run once or twice a year, or on demand. The benefit of the workshop is that it is run in the context of a support group so ongoing support for group members is already established.

Course/workshops on parenting and living with HIV

This can entail organisations developing a course running over a 6- or 12-week period, covering a multitude of issues and activities and giving parents/carers time for reflection. Again, having as a facilitator or co-facilitator someone who has

PRACTICE EXAMPLE 4: BODY & SOUL

Teenage facilitators

Adult support sessions enable parents/carers to talk to their peers about disclosure, and they can hear others share their experiences and ask questions. The use of teenage facilitators who have experienced disclosure has been extremely successful. Sharing openly with parents/carers over issues such as when the young person ideally would like to have been told, by whom and where, are invaluable tools to support parents/carers in working towards open dialogue with their children.

These workshops provide a forum for the young people to put forward issues on why they believe they should be disclosed to. These include having a sense of control, preventing feelings of isolation ('Is it something I've done wrong?'), helping them make informed decisions and explaining confusing or disturbing events. Additionally, facilitating a workshop is an empowering experience for the young people involved, and helps develop self-esteem and confidence.

Body & Soul is a charity based in London that provides support for children, teenagers, women, heterosexual men and their families living with or closely affected by HIV/AIDS. For further information visit <http://www.bodyandsoulcharity.org>

experienced bringing up children and talking openly to them about living with HIV will be useful. Service user involvement and sharing of experiences is invaluable, but good facilitation is required to ensure that all opinions are accepted and that parents/carers who are not yet ready to talk openly to their children do not feel negative about their choices.

Ongoing support needs

My fears and problems will never go away; I continue to learn how to cope with them. (Sarah, aged 17, HIV+, in CWAC 2004)

Parents/carers may want to access ongoing peer support in addition to one-off sessions and courses. Developing parent/carer peer support groups can offer the opportunity to explore all aspects of living as an HIV-infected parent/carer, including bringing a child up in an alien culture, coping with periods of ill health, and talking to children about sex and HIV. Again, a consultation will explore the issues the group wants support with and direct the content and structure of the group.

It is important to appreciate the cultural norms and values of the client group. In some cultures, it is not the norm for parents/carers to talk openly with their children about any personal matters; other adults in the community may serve this role. Parents/carers may require support with any 'fall out' after talking to their child about HIV in their family, and then ongoing support when issues arise as time goes on. Thought needs to go into who is the target group for this service. For instance, will a positive parent/carer group be open to, and provide an appropriate service for positive teenage mothers or positive gay parents/carers, or do they need access to separate support services?

Not all services can offer ongoing support or access to peer support groups, but being aware of what is available in your area, and alerting parents/carers to what is available to them is fundamental if there is nothing further your own organisation can offer.

I don't talk about it at home, it's too painful. I feel tearful even though I've grown up. (16-year-old, in Positive Vibes 2004)

Family outings

Families living in areas of low HIV prevalence may not have the option of accessing a parent/carer support group or a family service. In this situation, families can be brought together to share experiences and build supportive relationships through other means, such as outings and one-off events organised by key practitioners who undertake direct work with the individual families.

PRACTICE EXAMPLE 5: LEICESTERSHIRE HEALTH

Faith in Families with HIV outings

The children's HIV specialist nurse in Leicester, which has the second largest number of HIV positive children outside of London, was concerned that HIV-infected families, the majority of whom are of sub-Saharan origin, were particularly isolated. In partnership with local voluntary organisations, funding has been secured to facilitate the development of supportive relationships through 'Faith in Families', which is the name given to the regular family outings that have been organised.

These outings run during school holidays, are entirely funded by voluntary sources and aim to promote inclusion for all the families accessing paediatric HIV services. Outings have included visiting a local theme park. Parental evaluations consistently reveal an appreciation for spending time with other families in a similar situation.

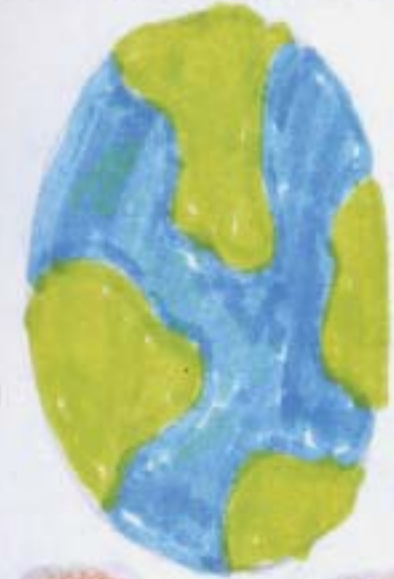
Peer relationships have now been established between many of the families who are maintaining contacts between clinic visits and outings. This has proven to be a positive tool in bringing together isolated families.

Sometimes when you talk about your experience the burden is heavy, but when you talk to someone in a similar situation the burden is off-loaded and you give each other strength. (Parent)

Leicestershire NHS Trust is a statutory health care provider. For more information about 'Faith in Families with HIV' contact Juliet Houghton (juliet.houghton@uhl-tr.nhs.uk).



This time I wasn't very very sick.



3 Supporting young people

My life revolves around medicines

3 Supporting young people

Young people are a diverse group with differing experiences, needs and lifestyles. This section presents some of the issues faced by HIV-infected and affected young people living in the UK, and then ways to support them, both through individual support and within their peer group.

Adolescence is a time of change in all children's lives, physically, emotionally and behaviourally. It can be a particularly challenging time for families as well as for young people. Even when they have their HIV infection in common, how they were infected and their family circumstances, culture and life experiences will impact upon the nature and manner of support they may want to access. For example, a young person who was infected through mother-to-baby transmission (vertical infection) will have different experiences and needs from a young gay man who contracted HIV through consensual sex. If that young gay man then accesses a support group where all other members are young people infected from birth, this may only intensify his isolation and exclusion rather than addressing it.

To that end, it is fundamental when developing services to be clear who the target group is and to involve them in the planning and developing of the service. It is important to consider what organisations and environment this target group would most naturally gravitate towards, whether there are specialist services that can support them in their additional needs (young people's drug projects; young lesbian, gay, bisexual and transsexual [LGBT] groups) or where they may feel more comfortable. Finally, this is a hugely diverse age group and therefore the very different stages of development these young people will be at must be acknowledged.

Issues faced by young people

Young people may face many dilemmas, choices and decisions in their lives, from those around drink, drugs and sexual health to those concerning careers, education and employment. This section looks at the issues specific to living in a family where there is HIV. It is important to remember that, even if a young person lives with HIV, they need to be able to be 'normal' and to do things other young people do.

When developing work with young people, good links with statutory and voluntary services will be important in bringing in expertise on specific topics and referring young people to other services when they need specialist inputs (e.g. drugs-related youth agencies, teenage sexual health or mental health information). These services can supply important information or assist a project in its activities. They may, for example, have youth facilities that can be used by marginalised groups, or be able to offer work experience opportunities.

Disclosure

Because I was in hospital, I wanted to know what the medicines were I was taking. She started showing me some of the pills and capsules I was taking. She started going on about HIV and I said, 'Well am I?' and she said 'Yes, we have reason to believe you are' (HIV+ child, in *Voices of Children*. CWAC)

Within this age group, the expectation would be that, at some point, the young person would be told about their own or a family member's HIV infection. No one can determine how young people will act following disclosure; they may feel anger, depression, fear, rejection, relief, guilt or injustice. The process of disclosure has to be flexible and there is no single model that can be followed. A number of resources have been produced specifically on disclosure for parents/carers and professionals. These include *Where Do I Start? Talking to Children with HIV about their Illness* (St George's Paediatric HIV Team 2003), *Talking with Children about Illness and HIV* (Penny 1999) and *Talking with Children, Young People and Families about Chronic Illness and Living with HIV* (Miah 2004).

The main guide for disclosure is that it is an ongoing process, not a one-off event. In the case of the infected child/young person, disclosure will involve a multi-disciplinary approach, involving parents/carers, paediatric HIV health professionals, social services and/or voluntary sector support. The affected child/young person may not have access to health specialists, and parents/carers may rely more on peer support and support accessed through voluntary and community groups.

Having access to a peer support service prior to disclosure has been shown to be of great benefit to many young people. Knowing that support is already available and that you are not the only person who is infected or affected by HIV can be of great comfort. Young people are more often at ease talking with their peers than with adults and professionals.

What I really enjoyed about today was the idea of having to freely discuss issues regarding HIV. I got a chance to talk about my own experiences without feeling restricted. And I also got to hear other people's views about HIV and their experiences. (Affected young person, Karibu 2004)

This process of disclosure does not relate to the young person infected through sex or sharing injecting equipment. Their diagnosis on the whole will be within the context of adult services. The hope is that adult services will liaise with paediatric services to ensure that the young person has appropriate support and health care. Adolescent HIV clinics are starting to develop, but at present there are only a few running. This is a group that is extremely isolated and there is little peer support available to them, but they are growing in number and must not be overlooked.

Future

I want to get a girl who loves me and get married and get a job. (Young man, HIV+, in CWAC 2004)

For all young people, the future can sometimes be a concern. For the infected young person, questions such as 'Do I have a future?', 'Can I have children?', 'Can I have sexual relationships?' and 'Am I going to die soon?' can all arise. For others, economic survival is an important issue and questions such as 'Who wants to employ me?' are as relevant. An HIV-infected young person may set themselves shorter-term life goals than other young people. Both infected and affected young people can have concerns about what the future holds for their family: 'What if my parent gets ill or dies; what will happen to my family?' These fears will not be dispelled in the short term and could cause a change in the young person's overall behaviour and approach to school, friendships and family.

Building up a picture of life now, including their family history, can assist in this area. This can include working with parents/carers and young people, using photos, pictures, diaries and newspaper cuttings to map the parent's/carer's life and when the parent/carer acquired HIV, and the young person's life, concluding with their hopes for the future. This family history places the child in a larger context and offers understanding of where they have come from, and where they may go in the future.

Bereavement

It hurts at first, so painful, and every time she gets ill, that pain comes back. (Affected young person, Karibu 2004)

Young people may have already suffered one or more bereavements through HIV/AIDS in their family and have been unaware of the cause of death at the time. They will fear for their HIV-infected family member(s) and may, during their time at a service, suffer bereavement. Also, an infected child who accesses a service may die, so work around the issue of loss and bereavement will be beneficial in one-to-one and group work with young people.

Being aware of the different cultural expectations of bereavement and incorporating these into work on this topic is important. This could be a useful tool to instigate group work focusing on the abstract premise of how different cultures grieve. Workshops on loss and change can be helpful preparation tools that allow supportive relationships to develop between young people. Such supportive relationships will be invaluable to a young person who undergoes bereavement through HIV/AIDS, as the group may be the only place outside their family where they can be open about the cause of the death.

There are organisations working specifically with children and young people who have suffered bereavement. Building links with these and developing either joint work or a referral process would benefit both the children and young people and work towards the 'normalising' of HIV in children's services.

PRACTICE EXAMPLE 6: JIGSAW4U

Childhood bereavement services

Jigsaw4u provides a number of grief support services that include home visiting, buddying, weekend respite and peer support. Grief support initially focuses on the family, and within that context, the family decide how they are going to refer to the cause of death. For example, in the case of an AIDS-related death, the family may choose to define this as a blood disease.

Children have the opportunity to participate in a time-limited bereavement support group that consists of seven sessions and a non-residential weekend. These run for children under 10 years old, and those over 10 years old. Grief support provides the opportunity for children who are feeling alone and different to meet up with children with similar experiences. Group support provides activities that enable participants to develop coping strategies.

Because group work focuses on the bereavement, children and families who have lost members through stigmatised illnesses such as HIV/AIDS, and stigmatised deaths such as suicide and a drugs overdose, feel they can participate fully and gain much.

What's so amazing is that it's not Jigsaw4u working *for* you but *with* you – I felt so alone and different before getting involved with Jigsaw4u – it's like having another family – you go to their groups meet lots of people and make friends because they all understand how you feel...and you can stay involved as long as you want, 'cos you can get involved in making the young people's magazine, go to family events and text whenever you need to. (Michelle, 15)

Jigsaw4u is a charity dedicated to working with children and families in crisis across south-west London. For further information about the organisation and the services it provides visit www.jigsaw4u.org.uk, email annedavies@jigsaw4u.org.uk or call 0208 687 1384.

Carer for family members

Young people may be expected to take on different roles and responsibilities within the family. These roles can be in relation to caring for a parent/carer in times of ill health, or caring for siblings when either the sibling or parent/carer is ill. HIV can impact on both physical and mental health, and due to these circumstances the young person may become the primary supporter for a parent/carer. In addition, there may be a cultural expectation that young people take on a caring role for younger siblings. Awareness of all of this is extremely important, as the level of caring expected of the young person may start to impact upon their well-being, and could become a child protection issue.

As a young carer, a young person may be entitled to additional specialist support. Locating and building links with local and regional services that support young carers will benefit young people who may gain additional support, and will again be working towards raising awareness of and 'normalising' HIV in children's services.

Cultural diversity

There can be extra pressure on young people whose parents/carers grew up in other cultures. This can produce issues such as conflicts between a young person's value system and experiences growing up in the UK, and their parents'/carers' expectations that reflect their experiences growing up in a different culture. Young people may need help in understanding that their parents'/carers' experiences differ from their own. This is not about taking sides, but understanding diversity and difference and acknowledging its influence in the parent/child dynamic.

Relationships

I have no one to talk to who understands my feelings. (Young person, HIV+, in CWAC 2004)

Peer relationships are a fundamental part of childhood. HIV-infected young people can struggle to maintain friendships and relationships. The burden of secrecy of their HIV infection can make them feel isolated, introverted and different. They may at times seem preoccupied. Periods of ill health can impact upon their confidence and result in time out of school, which then impacts on building and maintaining peer relationships.

Affected young people may also struggle at times with the secret they carry, or the feeling of not being the same as everyone else. This can impact upon building and maintaining peer relationships, which is why having a confidential group where everyone knows they are infected or affected by HIV can be so positive for many young people. Although a balance is important, as infected and affected young people also need to maintain a 'normal' life, interacting in generic clubs and youth activities, and forming peer relationships outside HIV and HIV services is useful.

I think it's good because [young people] get to meet people who are in the same situation as them and you feel more good when you're with people who know what you're going through. (Young person, Karibu 2004)

Within the context of relationships, the issue of sexual relationships is likely to arise. An infected young person may ask questions on whether they can have sex,

how to protect themselves and their partner, and seek advice on disclosure in this context. Infected and affected young people may view sexual relationships with fear, as this is where one could potentially acquire HIV. Establishing links with sexual health advisors from sexual health clinics and then supporting young people in accessing this expertise would ensure that young people are given the most up-to-date confidential information. These links could also be utilised to run a sexual health session as part of peer support work and to help train staff.

Siblings

I've rarely had people over. My brother and my sister – yes, they have people over. Mum...she doesn't want me to...I think it's because I'm positive. (Peter, HIV+, 11 years old, in Lewis 2001)

HIV can heighten complexities within individuals and family dynamics. An HIV-affected sibling may not be aware of the family's HIV infection, but experience jealousy if an infected sibling is seen to get more attention due to their ill health. They may also feel 'left out' or angry, as the family secret is not shared with them. These confused emotions may become guilt when they discover that their sibling is HIV infected, and this may intensify if there is a period of ill health or bereavement. An infected sibling may feel they are treated differently and not given the freedom their siblings have. Young people may need to explore their 'place' or 'role' within the family and the positive and negative aspects of this can be explored in individual or group work.

Chronic illness and body image

When you are HIV, you are still someone with emotions, feelings and dreams. (Sarah, HIV+, in CWAC 2004)

HIV-infected people can suffer from a poor sense of self and of body image. For the HIV-infected young person, the virus can delay puberty and the drugs regime can cause physical symptoms. Combine this with adolescence, when awareness of body image is at its peak, and many HIV-infected young people struggle with this. Building young people's self-esteem and self-worth is extremely important, both when working with individuals and with peer groups. The importance of 'rules' for a peer group on respecting and supporting one another is essential in this context, as peer groups can reinforce individuals' negative self-image. A sense of self-worth can be developed within the opportunities offered to individual young people within an organisation. Having the chance to volunteer, mentor, facilitate groups and undertake work experience will all work towards a positive self-image and a greater sense of worth.

Adherence

...remembering is really hard – it can be a pain – you think ‘Oh, do I have to?’ It’s not going to kill me for one day. (HIV+ child, in *Voices of Children*. CWAC)

Many infected young people will be taking HAART (Highly Active Anti-retroviral Treatment). Ongoing adherence is crucial with HIV medication as even missing one or two tablets a week can lead to the virus becoming resistant to those particular drugs. Adolescence can be a troubled time, and taking medication may not be seen as a priority, may be forgotten or may be used as a form of control. Positive attitudes to medication, good relationships with health workers and positive reinforcement are all important in supporting young people in maintaining their health through adherence.

Wider disclosure

I feel sad that I can’t tell, have to keep it a secret because I know people won’t want to be around me or like me. (Young person, HIV+, in CWAC 2004)

As was mentioned previously, the secrecy that HIV demands can, at times, impact upon the emotional well-being of both infected and affected young people. Development through the teenage years means that young people move away from the family and towards independence, and part of this process is confiding in and gaining support from friends. Many young people benefit from peer support groups as they offer the opportunity to develop open peer relationships.

Meeting people my own age who are going through a similar situation to me and who understand how I feel really helps. (HIV+ child, in *Voices of Children*. CWAC)

Living with HIV means that young people develop their own understanding of confidentiality and trust, and this will vary due to experience and what they have been told. Young people may need to explore and discuss wider disclosure. This includes who they want to tell, who they feel ought to know and the issue of telling potential or current sexual partners. In the context of a group, involving or inviting along either adults or young people who have been through this and can share their experiences will be beneficial.

Supporting young people

There are many ways of working with young people and much has been produced on techniques and tools. This section presents a number of different ways of looking specifically at exploring issues that could arise because of HIV and offers examples of current practice. See Appendix 1 for a list of resources.

Support can easily be divided into two categories: *individual support* and *group or peer support*. Both have a place in the process of living with and talking about HIV, and individuals may prefer one to the other or find both equally as useful. Other support could be 'long-arm' support through email, letter writing or on the telephone, set up by key practitioners working directly with isolated young people.

I need to be in touch with other children who are affected or infected with HIV. I want education, information and a teens support group that directly addresses the issues. An adult who is HIV+ should tell the group their story. I'd like to play games, activities and workshops. (16-year-old, in Positive Vibes 2004)

Consultation

Good practice dictates that involving service users in developing services is essential. Simple consultation techniques can engage young people and support them in exploring their support needs within the context of the organisation and the funding available. It is good practice when consulting with young people to try to ensure the service is developed in a short time-frame once their opinions and feedback have been gathered (see Practice example 7).

Individual support

Sometimes I get stressed but I manage to cope. (Affected young person, Karibu 2004)

Support does not have to be seen solely in the context of a group or counselling. Simple but imaginative ways can provide an individual with the support they need.

A young person may not want to attend a group, but they may enjoy building relationships through letter and/or article writing, emailing, or through activities with a designated member of staff. Through all of these, hopes and fears can be shared, questions can be answered and significant relationships can be built (see Practice example 8).

Family support worker

If a young person is accessing a service that works with families, they may benefit from building a significant relationship with a family support worker. This person can offer respite for the parent/carer and support the young person through harder times, both related and unrelated to HIV. The young person may see them as an adult they can relate to and with whom they can share what they are feeling. The worker may be able to work through some of the young person's issues and refer them to other services and activities.

PRACTICE EXAMPLE 7: CHILDREN AND YOUNG PEOPLE HIV NETWORK

Consultation for developing a young people's group

The Children and Young People HIV Network was invited to undertake a consultation for developing a young person's support service at Karibu in south London. The consultation was run throughout the afternoon using a number of tools to promote group and individual thought and discussion on all elements of service development. A relaxed atmosphere was created through music, food and access to art/craft equipment.

Images and pictures were displayed on boards depicting activities and interactions (individual, group, fun, etc.) to engage all those present in thinking about what they would like to develop. Stickers and a grading system allowed participants to record their views. A 'Comments Box' and cards were available so that participants could make confidential comments about the service that they wanted developed.

The main aspect of the consultation was a 'diary room', set up in the style of the television programme *Big Brother*. The young people were called over a PA to come to the diary room, where they were interviewed by a voice from behind a screen. In-depth interviews were conducted, in the manner of *Big Brother*, to explore individual opinions and feelings towards establishing a group.

What I liked about today was that everyone was involved in the activities, we got together and I got to meet my friends. Talking about what affects our family units.

Children and Young People HIV Network is based at the National Children's Bureau and works nationally to promote the voice of children and young people living with HIV in the UK in policy and practice development. For further information visit www.ncb.org.uk/hiv

Peer mentors

Young people will often relate to and confide more with members of their own peer group rather than with adult workers. Relationships with other youth similarly infected or affected by HIV may prove an important source of support. A system of peer volunteers or mentors can be developed within the context of a support group or as part of an organisation's volunteer programme. Young service users who are quite confident and well practised at talking about how HIV impacts on their lives may wish to act in this role.

A mentor or volunteer may be paired with a young person to offer friendship, support them in accessing services provided by the organisation and share their experiences. Within the context of a group, mentors or volunteers can be assigned to new group members. The volunteer or mentor's role is to carry out the new member's initial induction, introduce them to other group members and perhaps

PRACTICE EXAMPLE 8: HEALTH THROUGH ACTION

One-to-one work with children and young people

Health Through Action is a Barnardo's project that supports children and young people living with HIV. A team of social workers offers direct support to children who know about their own or their family's HIV status.

Workers establish a relationship with the child at their pace, following their agenda. Age-appropriate therapeutic activities such as play, cookery and physical activities are used to create an environment where children can safely express themselves. Most children want to talk about their emotions as a whole, and the complexities of their family situation and their own lives. Although they are not forced to speak about HIV, the ethos of the project is that workers will not collude with children to not speak about it, so the worker will initially be proactive in mentioning HIV until the child decides they want to talk about it.

I have someone to talk to who understands what I go through. (Young person)

Barnardo's **Health Through Action** is a charity based in Manchester. The project has a team of specialist social workers that offers support services for children, young people and their parents/carers living with HIV. For further information contact the project on 0161 273 2901.

call them after the group meeting for the first few weeks until the new member feels more established in the group.

The volunteer or mentor must receive training and supervision to support their role. Volunteers or mentors can provide 'long-arm' support and communication with young people who, for different reasons, are unable to attend group meetings; this can include email contact, writing letters or telephone calls.

This role may develop further. Peer volunteers may feel confident enough and express a wish to extend their role, undertaking talks in school and colleges, as well as at conferences and in the media, to advocate on behalf of young people and have their experiences and wishes heard. Such work can be empowering and enhancing in terms of life skills for young people, but they must be sufficiently supported when undertaking such activities.

Educational support

With increased disability and learning/school-based problems, as well as the impact of living in a family with a chronic illness, both infected and affected young people may need additional educational support. This could be by accessing formal support through local education authorities or through running

homework clubs where young people can access support with their work and have a quiet place to study.

Work experience and freelance paid work

For me, it's not so much the HIV that bothers me any more, it's more wondering about how I'm going to pay my overdue bills. (Young person, aged 18)

For young people over the age of 14, educational support and employment opportunities become far more of a pressing issue. Within an HIV organisation, some young people may enjoy an office environment and activities such as database work, research, creating publications, performance art projects and social interaction around devising activities or being supported to re-enter education. This builds self-confidence and self-worth and offers an opportunity to develop workplace skills.

Overall it is the organisation's responsibility to provide the young person with the best possible services available, and this may include onwards referral to another HIV-related organisation across the sector to gain work experience. When working

PRACTICE EXAMPLE 9: CHILDREN WITH AIDS CHARITY

Work experience

Society expects everyone who is healthy to work, and many young people living with HIV beyond the age of 18 are currently living in good health and want to work. The DLA (Disability Living Allowance) places certain restrictions on claimants and these mean that most young people need to find a way to juggle the aspects of living on benefits and striving towards independent living while they make the transition from paediatric to adult services.

CWAC offers HIV-infected young people opportunities to work. As volunteers they undertake work that will broaden their workplace skills and increase their potential in the work market. Additionally, CWAC actively seeks paid work opportunities through freelance work and supporting young people through the job application process.

When I first came to CWAC I thought that I wouldn't end up working here because when I arrived I had nothing... I've now been working here just over a month and love every minute of it. Now I love waking up in the morning to go to work because at work I can help change someone's life for the better and I have meaningful things in my life to focus on and improve. It's an honour. (Kevin, affected young person)

Children With AIDS Charity is a national charity with the simple aim of working towards a future without prejudice for these children and their families. For further information, or to view their publications and resources, visit <http://www.cwac.org/> or telephone: 020 7247 9115.

with young people, developing and maintaining constructive relationships with a wide range of external agencies is crucial.

Group activities

Holiday schemes

Summer holiday schemes can offer daytime outings and activities for all families accessing a service; participants generally include both those who are aware and those who are not aware of their family's HIV status (i.e. they are 'mixed knowledge' groups). The focus is on bringing families together and providing subsidised or free family-focused activities. They are also an easy access point for families that want to come to the service but are not yet ready to join support groups.

PRACTICE EXAMPLE 10: KARIBU/PPC

Summer holiday play schemes

Karibu and PPC between them cover a large section of south London and both organisations offer a well-established summer holiday scheme for children and young people aged between 5 and 16 and their families. The scheme is open to all families living with HIV in the area, and includes both children who know and do not know that they live in a family directly affected by HIV.

A variety of free planned activities, both centre-based and outings, provide structure and an environment that children and young people can identify with. Within this structure issues such as school and home life, relationships, sexual health, drugs and bullying can be addressed in a variety of sensitive and responsive ways.

The aim of the scheme is to give children and young people the opportunity to try new things, build friendships, engage with their peer group and have a break from home. It offers informal education through broadening horizons and experiences. For the parents/carers it offers respite, reprieve from financial pressures in relation to child care and a safe place for their children to go.

Thank you April for inviting me to the play-scheme, I have had an excellent time and I enjoyed everything. (Service user, age 7).

Karibu is part of Wandsworth WelCare and offers services for families living with HIV/AIDS. For further information contact info@welcare.org.uk or call: 020 8767 1020.

Positive Partners/Positively Children (PPC) is a locally based voluntary organisation, which predominantly works with children and parents/carers from minority ethnic groups infected or affected by HIV/AIDS. For further information visit <http://www.ppclondon.org.uk/>

Residential breaks

Residential breaks can offer a number of opportunities for a group of young people who are aware they are living with HIV. These can be time for reflection, building peer relationships, undertaking structured activities and having fun together. Where funding is available, residential breaks can be used for consultation, where the group undertakes a number of activities to explore their views.

PRACTICE EXAMPLE 11: NEWHAM PRIMARY CARE TRUST'S CHILDREN'S RIGHTS COMMISSION

Residential consultation

The Consultation Project was specifically designed as a new way of working to include, involve and gain the active participation of young people in the design development, planning, commissioning and coordination of services. A three-day residential for young people infected and affected by HIV was run to test out the following assumptions:

- ◆ Young people have unmet support needs
- ◆ Young people lack information
- ◆ Many young people are at especially high risk of acquiring sexually transmitted infections including HIV.

The event provided a programme of structured work and social activities designed to enable young people to reflect, learn and grow from their shared experiences. Activities included a number of team-building activities (climbing, canoeing, swimming); exercises to explore the ways in which the group wanted to conduct and chair meetings; exercises to consider the interpersonal dynamics; exploring developing the group and the emerging issues and needs; and personal testimonies through individual interviews.

This weekend opened it up. I would like to keep it going, see more people, to know more information about the effects of the medication. I would like to tell the Mayor of Newham to support us and tell him what we're going through. I would like a homework group, fun activities, to make a video about us – the group talking about the group, to educate others and more residential trips. (16-year-old, in Positive Vibes 2004)

In response to these specific issues affecting young people, Positive Vibes, a young people's group, was set up in Newham.

Children's Rights Commission is part of Newham Primary Care Trust. For further information about this aspect of their work and about Positive Vibes, contact Dipti Morjaria, Dipti.Morjaria@newham.gov.uk

Peer support

Group work and peer support can be a very effective method of working with children and young people. Those who do not respond well to one-to-one therapeutic interventions may respond better in a group of their peers. When developing group work, it is essential that young people are involved from the start.

Areas to cover in consultation

Consulting with proposed members will present clear findings to direct the development of a group. Preparation and planning should be undertaken to ensure that the exercises and activities run during the consultation cover all the areas that views and opinions are needed on.

The following issues will need to be defined within the activities:

- ◆ **Who can become a member of the group?** There is good cause to state that the need is for a group that knows, otherwise this group will just be a 'youth club' and will not address the specific needs of those living with HIV. Activities exploring the need for confidentiality and trust when openly talking about HIV will place this issue firmly in the thoughts of participants.
- ◆ **General formalities.** These include issues such as how regularly the group will meet and where would be the best place for the group to meet. Young people need venues accessible by public transport. They may prefer to meet in a young person's venue such as a youth club, rather than an HIV organisation's building.
- ◆ **Structure and content.** What will the focus be? Is it therapeutic support, social support, activities-based, participation or a mixture of all of these? This will also dictate who should facilitate the group. It is strongly advised that at least one facilitator has youth work experience, and ideally experience of working with HIV, or children living in other vulnerable situations.
- ◆ **Identity.** A group needs to set their own 'rules' or ground rules. These need to in some way reflect the organisation's equal opportunities policy, so running exercises and activities to explore these is important. Part of forming the group's identity is for them to choose a name and if possible a logo, or design that represents the group. This can be through activities or a competition where all members get a private vote.

Knowledge about HIV in the group

So young people can feel as if their family secret can be protected by others who also know, a place where you can relate and talk to people. (Young person, Karibu 2004)

It is important to clarify whether each activity, service or group provided is for young people with knowledge of their own or a family member's HIV infection, or

PRACTICE EXAMPLE 12: HEALTH THROUGH ACTION

Peer support groups

Health Through Action is a Barnardo's project that supports children and young people living with HIV. All children and their families referred to the service have been through the disclosure process.

Part of the service offered to children includes peer group support. Two groups run regularly, which are divided by age, one for 10–15-year-olds and the other for 16–18-year-olds. Young people lead peer support groups and participation is an integral part of this work.

Groups include opportunities for fun and social activities, issue-based sessions and opportunities to participate in the project's overall agenda, recruitment of workers and regional/national awareness-raising.

When I first started the group I was a bit nervous, but I'm fine now. In the group I find it very supportive. (Group member)

Barnardo's **Health Through Action** is a charity based in Manchester. The project has a team of specialist social workers that offers support services for children, young people and their parents/carers living with HIV. For further information contact the project on 0161 273 2901.

for both those who do know and those who do not. If an organisation is striving to meet the specific needs of young people living with HIV, then this must be a knowledge group, which is necessarily a closed group only for young people who explicitly know about HIV in their family.

Within this context, young people can build open peer relationships and explore themes that will support them living with HIV through activities such as music, sports, theatre, drama, dance, art and outings. Building a group such as this takes time, as peer interaction and trust are at the core. Maintaining the group as safe and confidential means restricting access, so for example, friends of members cannot access sessions, outings or events run by this group. The organisation or service may choose to run additional open activities or events, but these should not be attached to this group, as some young people may feel this compromises their need in this particular group to be able to talk openly about HIV.

Infected and affected young people together

I get to meet other children with the same worries as me so I know I'm not alone. (Young person, HIV+, in Health Through Action Project 2004)

In current practice, the majority of support groups include both infected and affected young people. There is certainly room to explore this further through a

consultation with young people to gauge their feelings on this, although it is important that it be done anonymously so that infected young people can speak honestly about how they feel (see Practice example 13).

Separate groups for infected young people

HIV-infected young people face very specific and personal issues that they may at times not wish to share with affected young people. Much of this will relate to their health and the fundamental impact this has on their lives. Providing a space where they can obtain information and share their experiences is extremely beneficial. This may be in the context of separate monthly groups or one-off sessions (see Practice example 14).

Participation

Current practice and government policy is aimed at promoting the participation of service users in ongoing service development. To this end, a peer support group

PRACTICE EXAMPLE 13: WAVERLEY CARE SOLAS

Focus work with children and young people

Waverley Care Solas runs group support through focused work and activities for children and young people aged between 4 and 16 years of age.

YAP (Young affected people) is a weekly support group for young people aged 12–16 years who know there is HIV in their family. The group meets on a Thursday from 4pm to 6pm and activities include issue-based workshops, outdoor pursuits, visits to the theatre, art workshops and peer support.

Friday Group is a weekly mixed knowledge group for 8–11-year-olds that runs an activities-based programme focusing on building peer support and interaction.

Tuesday Group is for 'Open Arts' for 8–16 year olds where they work with all art media.

As well as being able to access less formal support through the groups and throughout the week, the children and young people are able to book individual support sessions on Wednesdays.

I have been coming to Solas for two years now and have made lots of friends, we do lots of interesting and fun things and there is always someone there to listen to me if I need to talk about HIV or my family situation. (Jay, aged 14)

Waverley Care Solas is a charity based in Edinburgh, Scotland, offering support services, information and an informal meeting place for people living with HIV. For further information see <http://www.waverleycare.org/support.htm> or call 0131 661 0982.

PRACTICE EXAMPLE 14: NEWHAM PRIMARY CARE TRUST

'Looking Forward' young people's days

'Looking Forward' days are open to HIV-infected 12–18-year-olds who are aware of their diagnosis. The session evolved due to HIV-infected children living longer and needing to move to adult services.

'Looking Forward' days run during school holidays, four times a year. Initially a letter is sent to parents/carers informing them that their child will shortly receive an invitation to the day. An outline of the day's events is provided, including the topics that will be covered. Young people are sent two invitations and a telephone reminder prior to the day.

The day is held in a local church, away from the clinic setting, in a prominent location with easy access by 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 young people drive the direction of the sessions.

These young people have expressed how isolated they are because they cannot or are afraid to disclose their status to friends or talk about it to their parents/carers. They have expressed that these days offer them an opportunity to talk openly and honestly about their diagnosis.

Newham Primary Care Trust is an NHS health care provider. For further information about this aspect of their work contact Rebecca Wilkins, clinical nurse specialist: Rebecca.Wilkins@newhampct.nhs.uk

could have a participation focus, whether this is for a particular service or to comment on service delivery regionally. This can be an extremely empowering position for young people to be in, especially if they see their thoughts and ideas being acted upon (see Practice example 15).

Additional issues to consider

Talk about how we feel, talk about HIV [and other issues] if we wanted to, we decide. (Young person, Karibu 2004)

As the peer support group will necessarily be a closed group, it is worth noting that there have been cases reported where the parent/carer may say their child knows, when actually the young person is not fully aware. A simple 'interview' with all potential group members will ensure all present are aware of the nature of the group.

The facilitator may need to take the lead initially in talking about HIV, aiming to create a space where HIV becomes a friendly term and the young people

PRACTICE EXAMPLE 15: POSITIVE PARTNERS/POSITIVELY CHILDREN (PPC)

CRIB 'Chasing rainbows is our business'

CRIB is a monthly peer support group for children and young people aged 8–18 who are aware that they are infected with and affected by HIV. It is part of a children's participation programme and was developed as PPC felt that a specific space for children was needed after they have been told about HIV in their family.

CRIB offers a place for young people to talk about their experiences, which includes talking about living with HIV. It also runs team-building activities such as rock climbing and swimming. It is a closed group, to promote confidentiality, and the young people set the agenda. The group also participates in activity-based consultations on service development at PPC and on wider HIV and community issues in south London.

What we have achieved through CRIB:

- ◆ freedom of speech
- ◆ knowledge about HIV and AIDS
- ◆ meeting new people
- ◆ talking to people in the same situation
- ◆ having fun
- ◆ coping with HIV (not worried)
- ◆ making new friends
- ◆ young people's feedback.

Positive Partners/Positively Children (PPC) is a locally based voluntary organisation, which predominantly works with children and parents/carers from minority ethnic groups infected or affected by HIV/AIDS. For further information visit <http://www.ppclondon.org.uk/>

experience safety and security and are free to discuss the issues of how HIV impacts on their lives.

Ongoing groups may choose at times to explore emotional issues in relation to HIV, but at other times explore other issues such as bullying, racism, sexual health or drugs; encourage creative expression; facilitate workshops for writing and drawing as ways for expressing their feelings and issues and building self-esteem.

Young people should be encouraged to be active in the planning and development of the content of each session. Using tools such as a 'talk box', where any suggestions for topics or activities can be written down and posted confidentially can generate a wealth of ideas and actions. As a group develops, young people can be encouraged and supported in designing and facilitating sessions themselves.

PRACTICE EXAMPLE 16: NEWHAM PRIMARY CARE TRUST'S CHILDREN'S RIGHTS COMMISSION

Positive Vibes: young people's participation group

Positive Vibes, a group for young people who know that they are either infected with or affected by HIV, was set up through a residential three-day consultation run by the Children's Rights Commission at Newham Primary Care Trust. The specific issues affecting the young people have driven the priorities of the group, which are to:

- ◆ end the silence, stigma and shame
- ◆ provide young people with knowledge and information
- ◆ equip young people with life skills to put knowledge into practice
- ◆ provide youth-friendly health services
- ◆ promote voluntary and confidential HIV counselling and testing
- ◆ work with young people, promote their participation
- ◆ engage young people who are living with HIV/AIDS
- ◆ create safe and supportive environments
- ◆ reach out to young people most at risk
- ◆ strengthen partnerships with statutory and voluntary sector providers working with children and families.

The service runs fortnightly in the evening, and sessions alternate between socialising activities and developing the participation aspect of the group. In addition, the young people plan and run 'Parent Pamper' days, when they invite and 'treat' their parents/carers.

Children's Rights Commission is part of Newham Primary Care Trust. For further information about this aspect of their work and about Positive Vibes, contact Dipti Morjaria: Dipti.Morjaria@newham.gov.uk

Often groups may combine therapeutic-type activities and workshops with more social events such as parties, outings, sports, etc. Tools such as circle time at the beginning and end of a group for reflection, drama workshops exploring the expression of emotions and developing confidence in communicating, team-based games and stress-relieving activities can combine fun and support.

Accept that some young people will not want to access groups and give them some space to make their own decisions. Parents/carers may be keen for them to participate, but young people must attend the group because they want to.

PRACTICE EXAMPLE 17: BODY & SOUL

Teen Spirit: a support group of 13–19-year-olds

Teen Spirit is a weekly structured support session for 13–19-year-olds who know that they are infected with or affected by HIV. The group was formed in 1996 because the needs of this age group were not being met.

The aim is to provide long-term holistic support through meeting physical, emotional and social/welfare needs. The ethos is one of empowerment, offering opportunity and positive change to enable the young people to cope with multiple disadvantages that include depression, isolation and multiple loss.

Teen Spirit provides:

- ◆ structured support sessions, including a programme of facilitated workshops on HIV/AIDS and other issues relating to adolescence, e.g. sexual health, drugs awareness, conflict resolution, self-esteem and youth rights
- ◆ one-to-one support with a counsellor/youth worker
- ◆ information/advocacy on a range of issues, e.g. careers, relationships, housing and health
- ◆ regular group for HIV-positive teens to discuss the issues specific to living with HIV, e.g. adhering to treatments, coping mechanisms, disclosing to friends and family, etc.
- ◆ one-to-one/small group educational support
- ◆ complementary therapies.

It wasn't until I came and met other young people with HIV that I saw there was some hope. Not only have I made friends and learned about HIV, but also staff have helped me get somewhere to live. I feel I have a future. Here it feels like home. (Nancy, 17 years, HIV +)

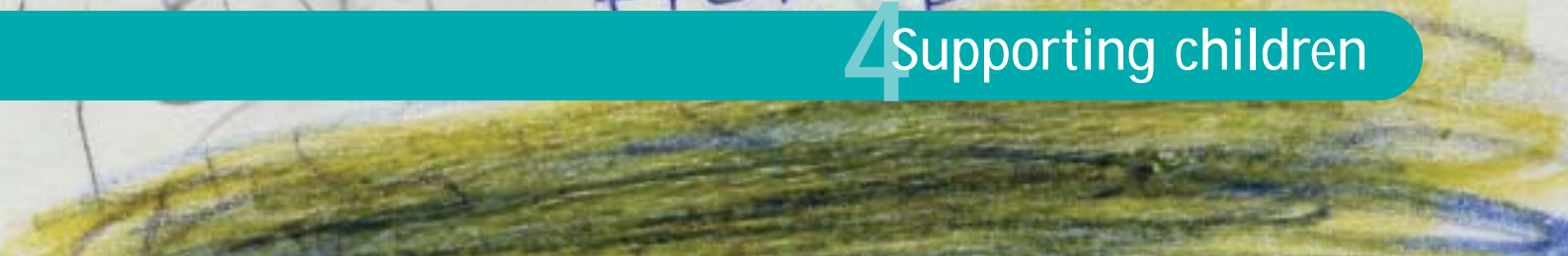
Body & Soul is a charity based in London that provides support for children, teenagers, women, heterosexual men and their families living with or closely affected by HIV/AIDS. For further information visit <http://www.bodyandsoulcharity.org>



at school with my sister
and friends in playground
field.



from Bertha age 7



4 Supporting children

It is fair to presume that the majority of both infected and affected children in this age category will not be aware of their own or their parents'/carers' HIV infection. This is generally seen as a preparatory time, to slowly introduce ideas and information to the child at age-appropriate levels. But not knowing the name of the illness that either you or a family member is living with does not mean that the illness does not impact upon your life.

This section will explore issues specific to children infected and affected by HIV; some are similar to those of young people and it would be advisable to read the previous section alongside this. Examples of support that can be offered to this group, both as individuals and through peer group work are given.

As with all the groups covered in this resource, the diversity of these children must be acknowledged. That diversity does not only span culture, life experience and ethnicity, but also the developmental stages that occur between the ages of 0 to 10. Therefore weight is given to both the child who is becoming more independent, developing relationships with significant adults (4–10) and the young child/baby whose experiences are so closely linked to their primary carer. At times in this section, these groups will be defined separately.

Specific issues faced by children

There are many other factors external to living with HIV that will influence a child's development and well-being. Factors will vary with individuals but what follows are key areas that need some consideration when developing work with this group.

Communicating and talking about HIV

Good practice dictates that the process of informing and educating children should be fluid throughout the child's life. Supporting parents/carers to have open and age-appropriate discussions on many different topics at an early age will normalise this form of conversation, nurture a relationship of trust and equip the child with the confidence to ask questions which can, at times, lessen their fear and confusion.

With this age group, disclosure generally relates to a parent/carer and significant adult talking to the child about HIV and chronic illness, whether it is the parent's/carer's diagnosis or the child's. But it can also be to do with how the child processes this information, and who they want to talk to about it. This is a complex issue and all parties may need extensive and long-term support with it.

*I found out at 9 years old by accident. I heard my auntie talking about my Mum. I didn't understand and took it as playing Doctors and Nurses.
(Affected young person, Karibu 2004)*

However well disclosure may be planned, many children find out by accident. What should also not be overlooked is the child having an intuitive awareness that something is not right with either themselves or a family member. Whether this is through taking medication, hospital appointments or periods of ill health for either themselves or a family member, the child will have some level of awareness. Research and consultations have highlighted that many disclosures occur by accident: a curious child finding a letter from the hospital or recognising drugs they take being spoken about on television.

Preparatory work with parents/carers and developing a multi-agency approach, including health, social services and the voluntary sector, can be a way of establishing child-centred discussions. In the case of accidental disclosure, it is important that all involved are working together for the child's best interests.

Being different

I don't like to run a lot and play a lot with my legs. I just want to stay at home. Sometimes I can't run a lot and stand. (Graham, HIV+, 11 years old, in Lewis 2001)

Whether a child is aware or not of the name of their own or their family's illness, intuitively they may feel different. Taking regular medication, regular medical contact and periods of poor health can reinforce that feeling of being different. If they are the only infected child in their family they may see themselves as 'different' from their sibling(s). As they enter mandatory education, both infected and affected children may also begin to realise differences between themselves and their peers. Again, this is especially so with the infected child. Therefore, they may need support in developing self-esteem and encouraging the development of peer interaction so they do not feel so isolated.

Emotions

I just come into my room. I spend most of my spare time on my own. (Tim, aged 10, HIV+, in Lewis 2001)

The emotions an infected or affected child may feel will vary due to their circumstances, health and situation. Specific feelings an infected child may have are fear of what is happening to them if they do not know their diagnosis, fear for the future, fear of what is happening to their parent/carer. They can feel confused, angry and sad about their situation and all that it implies.

An HIV-affected sibling may not be aware of the family's HIV infection, but experience jealousy if an infected sibling is seen to get more attention due to their health. They may also feel 'left out' or angry, as the family secret is not

shared with them. These confused emotions may create negative family dynamics which impact upon the child and parents'/carers' health and well-being.

Medication and treatment

Specific issues that may arise here are maintaining adherence when a child is taking medication. A child can often refuse medication as a 'control' response when having a difficult time. They will be experiencing the impact of taking highly toxic medication and the psychological impact of being a child who needs to regularly take life-saving medication. They may need simple encouragement and praise from those outside the medical profession, making them feel that taking their medication is a positive thing.

Child as carer

Children may start to take on a caring role at a very young age. This role can be in relation to caring for a parent/carer in times of ill health, or caring for siblings when either the sibling or parent/carer is ill. HIV can impact on both physical and mental health, and in some circumstances the child may become the primary supporter for a parent/carer. There may be expectations on the child based on the cultural norms of the parent/carer. Awareness of this is extremely important. Children should help in the family, but the degree to which they do so, and how it impacts upon their own well-being can become a child protection issue.

As was stated in the previous section, linking with specialist local and regional young carer organisations will be beneficial to all involved.

Supporting children

Children living with a chronic illness will need or require various levels of support depending on their own or their family's health and situation. Ways of working with these age groups has been documented and some examples can be found in Appendix 1. These proven techniques can be used within the context of HIV. It is fundamental to acknowledge that these are children first, and allowing them the space to be 'as normal as possible' will benefit them no end, recognising that at this age opportunities for play, games and fun are very important for children's development and well-being. Children need to take risks and push boundaries as this is part of their growth and development, and children living with HIV need to do this too.

Developing partnerships and accessing support from health practitioners will be invaluable for all involved. Multi-disciplinary HIV paediatric teams include specialist psychologists, nutritionists and health visitors as well as consultants and nurses. In addition, building partnerships with early years and children's organisations such as Sure Start and the local Children's Trusts, both of which have a remit for marginalised groups, may be a route to accessing equipment, facilities and expertise.

Support can easily be divided into two categories: individual support and group or peer support. Children may prefer one to the other or find both equally useful.

Consultation

Good practice dictates that involving service users in developing services is essential. When developing a parent/carer and/or child group, a consultation needs to be run with parents/carers to involve them in the design and development of the service. Younger children are often overlooked in consultation, but child-centred methods for this have been developed in other fields and these techniques can be used to consult with children living with HIV.

PRACTICE EXAMPLE 18: POSITIVE PARTNERS/POSITIVELY CHILDREN (PPC)

Bubbles: Saturday club and active participation for young children

'Bubbles' is a Saturday club for children aged 4–11 infected and affected by HIV. It is run by PPC in partnership with Positively Women, alongside African Families Support Services and Karibu. It aims to involve children who do not know about their own or family members' HIV status in commenting on and influencing service delivery.

Bubbles offers a mixture of activities, lunch, energiser games and outings like ice skating, swimming, bowling and go-karting. The content and structure of the group was developed through consultation with the group using structured games and activities. PPC's Children's Participation Program provides participation sessions as part of the Bubbles agenda.

This group ensures that PPC service development involves children of all ages at all levels. Through the activities and outcomes, the children not only see how their opinions count, they also build positive peer relationships, which will be beneficial as they find out about HIV.

Positive Partners/Positively Children (PPC) is a locally based voluntary organisation, which predominantly works with children and parents/carers from minority ethnic groups infected or affected by HIV/AIDS. For further information visit <http://www.ppclondon.org.uk/> or telephone 020 7738 7333.

Individual support

When Mum is ill, what would help is, sometimes, I think, if I had a dad who was living with me, or some kind of parent or helper. (Gerry, affected child, in Lewis 2001)

Family support worker

If a child is accessing a service that works with families, they may benefit from building a significant relationship with a family support worker. The worker can visit the home and promote parenting skills, parent/child interaction and play. They can also provide an element of respite for the parent/carer, which would be especially beneficial in times of ill health.

PRACTICE EXAMPLE 19: POSITIVE PARENTS/POSITIVELY CHILDREN (PPC)

Family support service

As part of its services, PPC offers a well-established family support service to infected and affected children and young people aged between 0 and 16, and their families, who live in Lambeth, Southwark or Lewisham (London). The aim is to build positive relationships with children, work closely with parents/carers to meet the children's needs and to offer advice and assistance to parents/carers in a way that encourages independence and confidence in parenting.

A PPC family support worker may support the family through providing practical child care; supporting the development of the parent/child relationship; giving support and advice; helping with behaviour management; and providing stimulating activities that promote the child's all-round development. The service is provided during the day, evenings and weekends, with 24-hour duty support.

PPC's family support service is a great help to me and my son, I am able to rest and feel secure knowing that my son is very well cared for. I feel that PPC's service has prevented me from maybe having my son fostered. My son has the opportunity to play and do things that I am unable to do. I also get support and encouragement from the family support worker.

Positive Partners/Positively Children (PPC) is a locally based voluntary organisation, which predominantly works with children and parents/carers from minority ethnic groups infected or affected by HIV/AIDS. For further information visit <http://www.ppclondon.org.uk/>

Group activities

Holiday schemes

As stated in the last section, summer holiday schemes can offer daytime outings and activities for all families accessing a service. They are a good tool for parents/carers to develop relationships and for children to interact with their peers (see Practice example 20).

Residential respite

It's hard to get the money to go on holiday because (Mum) doesn't work and we don't have a dad who works. (Carl, aged 10, in Lewis 2001)

As well as providing respite provision to individual families, respite breaks can also be provided for children, the aim being that infected and affected children are able to spend time together, away from home. These breaks provide welcome temporary relief from the build-up of the stresses of daily life, and, depending on the participants, may be designed to take into account the learning of specific life skills, for example, tolerance, delegation, self-awareness, self-confidence and team-building skills. For isolated young people, new friends can be made and certain aspects of living with HIV (such as taking pills in secrecy) are normalised.

Because of the economic burden placed on families living with HIV (e.g. being too ill to work or staying at home to look after a sick child), many are unable to afford to take a break during the year. Subsidised holiday and respite programmes therefore may also form an effective prevention strategy that serves to avoid more traumatic out-of-home placements like foster care (see Practice example 21).

PRACTICE EXAMPLE 20: WAVERLEY CARE SOLAS

Holiday programme

Waverley Care Solas runs holiday programmes through every school break for children aged 4–12 years. Some of the group know their parents'/carers' HIV status and some do not.

The aim of the holiday programme is to give respite care to children and their families. Activities offered include arts workshops, outings, swimming, computers, outdoor activities and general support.

I love coming to Solas in my school holidays, there is lots to do like swimming, soft play, trips to the cinema and I have lots of friends there to play with. (Cathy, aged 9)

Waverley Care Solas is a charity based in Edinburgh, Scotland, offering support services, information and an informal meeting place for people living with HIV. For further information see <http://www.waverleycare.org/support.htm> or call 0131 661 0982.

PRACTICE EXAMPLE 21: CHILDREN WITH AIDS CHARITY (CWAC)

Respite breaks project

A five-day residential break was organised by CWAC and Positively Women (PW) specifically for mothers and children aged 0–10 years who are infected with or affected by HIV/AIDS. CWAC was responsible for preparing the relevant paperwork for the trip and for making arrangements for transport, accommodation and activities. PW was responsible for corresponding with service users, arranging pick-up and drop-off arrangements, and for organising the mothers' forum and evaluation during the trip.

Activities included the whole group visiting a farm and a day trip to Brighton. Then the mothers participated in a workshop, 'Our Dreams for the Future', to discuss current issues surrounding parenting and living with HIV, which also included yoga and relaxation. During this time the children took part in an arts and crafts session.

The break aimed to enable mothers to spend quality time with their children without the stresses and strains of everyday life, and let the children experience the countryside and interact with their peers. It also offered the opportunity for mothers to get to know other mothers living with HIV, developing support and tackling isolation.

Being in a group of children and mothers who share the same illness and just being open about issues surrounding our illness. Very relaxed atmosphere. (Mother)

Children With AIDS Charity is a national charity with the simple aim of working towards a future without prejudice for these children and their families. For further information or to view their publications and resources visit <http://www.cwac.org/> or telephone: 020 7247 9115.

Peer support

Within current working practice in the UK, the presumption would be that a group for under-11s would not all necessarily know about their own or their family's HIV infection. But bringing together this peer group will develop relationships that can then be supportive of each other in living with HIV, growing up and eventually finding out about it.

Baby/toddler groups

Bringing HIV positive parents/carers into a group where the focus is on being a parent/carer of a young child/baby, rather than being HIV positive, can be easier for newly diagnosed mothers and fathers. It can take the pressure off parents/carers

who may not want to go to a positive parents/carers group, and allow for the building of friendships and support among those attending. This peer interaction, focusing on babies or toddlers, allows the development of relationships, through sharing and seeing others coping with being HIV infected and having a small child.

PRACTICE EXAMPLE 22: BODY & SOUL

The BaSe: services for 10–12-year-olds

The BaSe is a weekly support group for 10–12-year-olds who have mixed knowledge of how HIV affects them. Weekly workshops cover issues including bullying, managing conflict, keeping healthy, cooperation, friendships, trust and respect.

The service aims to provide:

- ◆ quality play and educational activities
- ◆ development of self-esteem and increased awareness of their right to shape the world
- ◆ development of life skills and attitudes so that children will be better able to cope when they are told how HIV affects them
- ◆ a sense of belonging where ongoing support is maintained after bereavement.

In addition, the BaSe runs a monthly group for 10–12-year-olds who know that they are infected with HIV. This provides a safe, confidential space in which the young people can form strong friendship networks through fun interactive games, build their knowledge of HIV and develop their self-esteem and confidence in order to begin to develop positive strategies for living with HIV.

This group aims to provide:

- ◆ structured support sessions, including a programme of facilitated workshops on issues including how HIV impacts on the body, adherence to treatments, strategies in coping with living with a secret, managing anger, etc.
- ◆ one-to-one/group education
- ◆ complementary therapies
- ◆ one-to-one support with an adult worker.

The positive BaSe is so important to me. Before I came here I was all alone and I thought that I was the only one of my age who had HIV. I had no one to talk to. My school friends don't know the real me. I could never tell them 'cos they would never speak to me again. In the BaSe I can just be myself and relax 'cos no one will judge me. (Rachel, 12 years old)

Body & Soul is a charity based in London that provides support for children, teenagers, women, heterosexual men and their families living with or closely affected by HIV/AIDS. For further information visit

<http://www.bodyandsoulcharity.org>

Peer support (4–10 years old)

Having the opportunity to express themselves creatively and through play can offer an outlet to many children. It may also offer an opportunity for them to express difficult emotions they are not able to articulate in speech. Encouraging children to choose topics they want to explore as a group through drama, dance, music, art and play will again all work towards positive self-esteem, improved communication skills and peer relationships, all of which will be beneficial in living with HIV. When planning group work it would be advisable to divide this group (into 4–6-year-olds and 7–10-year-olds), although this is not essential.

These groups and activities offer a perfect opportunity to start to give children factual information to help them have some control over what is happening to them, start to gain an understanding and feel empowered in decision making.

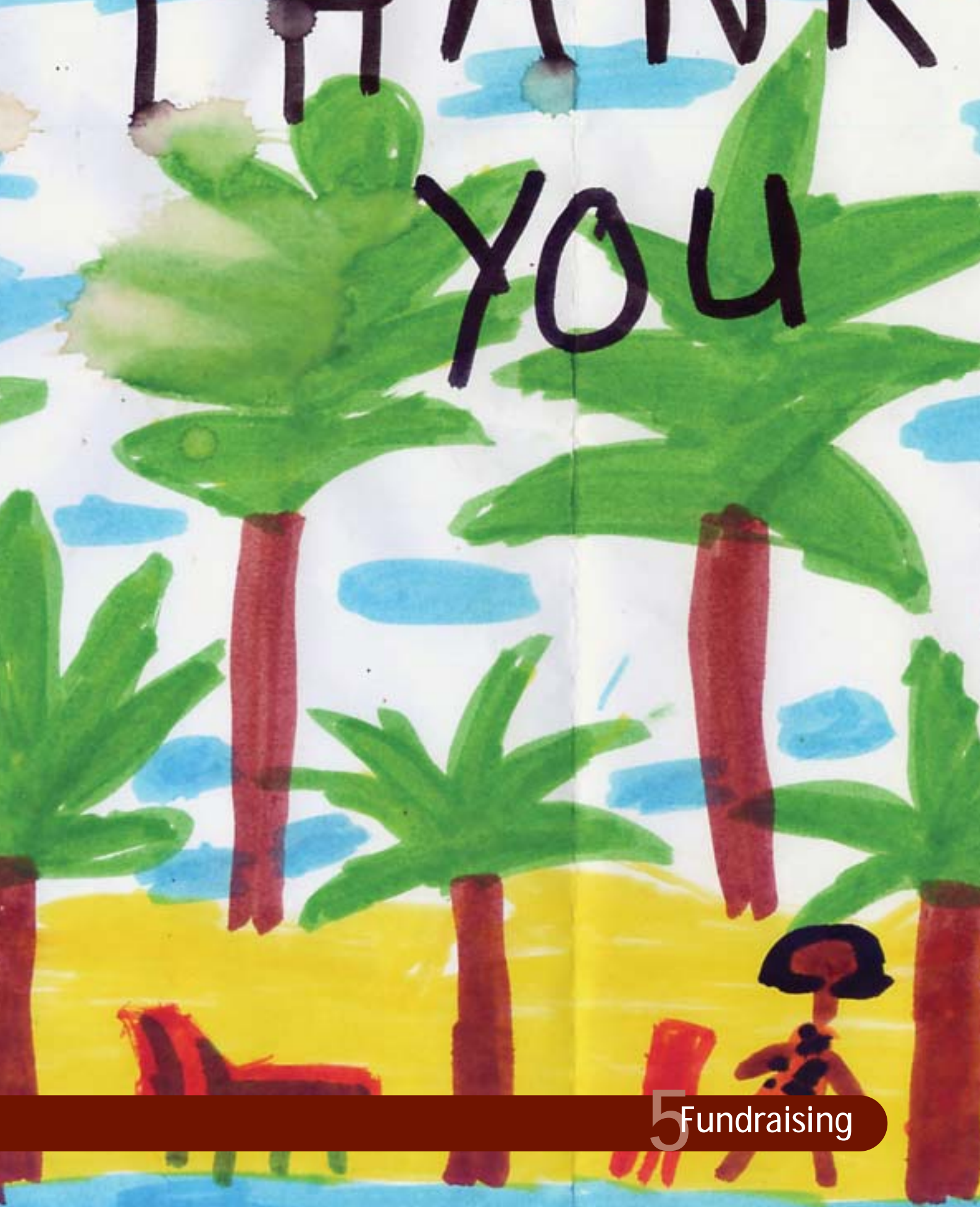
Children who know about HIV

You can play and talk so you can feel a bit happier and relaxed. (Infected child, in Health Through Action Project 2004)

Some children are aware of their own or their family's HIV status, and this group and their needs should not be overlooked. Within the context of services provided for children, a separate group may be formed to provide a place for these children to learn and share at an age-appropriate level with their peers. Combining children and young people in one group is an option, although careful consideration should be given to the content of these sessions, the needs of those attending and the language and information provided. A 17-year-old has very different needs and understanding compared to a 9-year-old. Children develop, learn and thrive through play, and therefore any work with this group should start from that premise.

THANK

YOU



This section offers practical guidance for obtaining funding for both individual and group work with families, young people and children living with HIV. It sets out the process that needs to be undertaken, including useful resources and publications, and then presents a list of some of the possible charitable trusts that may consider funding this work. There are no guarantees for funding, and all charities at times struggle to maintain their current work or to develop new work.

The idea

When actively searching for funds to develop work, some simple but important questions need to be asked in relation to the idea and work planned.

Consideration should be given to the following:

- ◆ Do you work for a registered charity and does the work planned fall within your organisation's charitable objectives?
- ◆ Are you planning to develop a project or a service? Projects have a start and an end date whereas a service can run indefinitely. For services, additional consideration needs to be given to sustainability in the long term and funders will want details on this.
- ◆ How much do you think the development will cost? It is important to have a rough idea from the outset to consider whether there are likely to be sufficient funding sources and whether you will approach more than one funder.
- ◆ Are the necessary systems, expertise, client groups and experience in place to make the idea or planned work possible? Links with partners who can offer expertise and assistance can make the bid more viable.

Research

Once the idea or work plan has been drawn up, it is important to ascertain what the likely funding sources are. This should ideally be done prior to investing too much time in developing the full proposal. The golden rules for this stage are:

- ◆ Avoid putting all your eggs in one basket. The chances are that you will ultimately be rejected by many of the funders you approach. Try to locate sufficient sources, which have the combined potential to give you at least three times what you require.
- ◆ Ensure you have the most up-to-date funders' guidelines. Use the funders' websites as these are regularly updated.
- ◆ When ringing prospective funders, prepare a few bullet points to ensure that you achieve all you can from this conversation. Do not call a funder if they specify they do not wish to be contacted by phone.

Resources

The following research resources may be of assistance. Please note that most of these can be accessed through local Council for Voluntary Service (CVS) or from a major library.

Free web resources

www.governmentfunding.org.uk Statutory funding website. Information on Department for Education and Skills (DfES), Department of Health (DoH), Home Office, Office of the Deputy Prime Minister (ODPM) and Government Offices grant programmes.

www.agemics.co.uk/grantmaker.asp This grant matchmaker service is a useful starting point for identifying trusts that have a propensity to give to particular activities.

www.charity-commission.gov.uk This site provides a searchable database of many of the charities registered. It is useful for getting basic information, e.g. address and contact names for trusts.

www.institute-of-fundraising.org.uk Website of the Institute of Fundraising. Check the special interest groups section and contact moderators for free membership of e-groups. Very useful for finding sources of funding and hearing about changes to grant makers.

www.grantsnet.co.uk This is a searchable database and email alert service.

www.altavista.com/web/adv This is an advanced web search using Boolean logic. It enables you to search the web for funding information using very specific search criteria.

Membership web resources

www.trustfunding.org.uk Directory of Social Change (DSC) trust funding website. This offers similar information to DSC paperbacks but is updated on a monthly basis. The cost of an annual subscription depends on the type of organisation you are, and the number of licences you would like to purchase.

www.debretts.co.uk This is a database of 28,000 biographies of prominent figures, books and guides. Annual membership at present costs £149.

www.fundinginformation.org This site offers sources of funding with details of application processes and guidelines from grant-making trusts and companies, Europe, government schemes and the lottery. At the time of producing this handbook, an initial free trial was available.

www.access-funds.co.uk This site aims to provide the latest funding information from central government, the national lottery, devolved governing bodies and the European Union (EU), and includes email services and training

courses. The site also contains directories of funding programmes and guides to funding. At present the site offers a free 7-day trial, but the headline page is always free.

www.grantsonline.org.uk This is a grant searchable database. It also has information on calls for proposals and associated websites. Annual membership is £150+VAT but it may be possible to get an initial free trial.

Other useful websites

www.dsc.org.uk This site offers lots of services including information about DSC's publications and training.

www.fundraising.co.uk This site has news, suppliers, a forum, events and a good book finder.

www.ncvo-sfp.org.uk This site offers information on sustainable funding.

www.ukonline.gov.uk This is the government information and online services site.

www.volresource.org.uk This site contains information for all types of UK charities, voluntary and community organisations.

Software

Funderfinder is a searchable database of funders that allows you to enter the type of person/group you are, what your aims/needs are, etc., and then prints off a list of possible funders. It is a good starting point if there is no existing database available. It can be purchased or is available at good reference libraries. Visit www.funderfinder.org.uk

The EU Grants Directory is available online for either £30 (CD ROM) or £25 (Internet download). It offers an EU update on a range of grant information available and calls for proposals. Visit www.europeangrants.com

Books

The Directory of Social Change has published *A Guide to the Major Trusts* (3 vols). It also publishes regional trust funding guides and has produced *The Guide to UK Company Giving*, which presents the top major UK donors. Visit www.dsc.org.uk/acatalog/Companies.html

The Charities Aid Foundation (CAF) has published *Directory of Grant Making Trusts*. Visit <http://www.cafonline.org/> for more information.

Possible trusts

The following are some charitable trusts that have in the past financially supported work with people affected by HIV/AIDS. It does not include all the trusts that support work with vulnerable and marginalised families, young people and children. It also does not include Primary Care Trust (PCT) Commissioners, who allocate funding through NHS budgets for HIV, sexual health, vulnerable populations and children in their local area. You should approach your local PCT to find out who the local or regional lead is to obtain information about their funding process. It also does not include the annual government funding streams mentioned previously (DoH, DfES, ODPM). All these sources are worth exploring in addition to approaching trusts.

Some charitable trusts – contact details

Comic Relief www.comicrelief.org.uk	020 7820 5555	The UK Grants Team 5th floor 89 Albert Embankment London SE1 7TP
Crusaid www.crusaid.org.uk	020 7539 3880	Crusaid 1–5 Curtain Road London EC2A 3JX
Henry T and Lucy B Cadbury Charitable Trust		BCM Box 2024 London WC1N 3XX
Kings Fund www.kingsfund.org.uk Lloyd's Charities Trust www.lloyds.com	020 7327 6075	One Lime Street London EC3M 7HA
Magdalen Hospital Trust	0121 445 1318	Cotswold Cottage School Lane Alvechurch Worcestershire B48 7SA
Mercury Phoenix Trust	01628 527874	The Mill Mill Lane Cookham Berkshire SL6 9QT
NAHIP www.nahip.org.uk	020 7017 8910	NAHIP New City Cloisters 196 Old Street London EC1V 9FR
The Body Shop Foundation www.the-body-shop.co.uk	01903 844039	Watersmead Littlehampton West Sussex BN17 6LS
The Diana, Princess of Wales Memorial Fund www.theworkcontinues.org/	020 7902 5500	The Diana, Princess of Wales Memorial Fund The County Hall Westminster Bridge Road London SE1 7PB

The Dorus Trust	01732 520083	Charities Aid Foundation Kings Hill West Malling Kent ME19 4TA
The Elton John Aids Foundation www.ejafuk.com	020 7603 9996	1 Blythe Road London W14 0HG
The JE Posnansky Charitable Trust	020 7431 0909	c/o Siedd and Co. 673 Finchley Road London NW2 2JP
The London Law Trust	020 7412 0050	Messrs Hunters 9 New Square Lincoln's Inn London WC2A 3QN

Developing the proposal

Time will need to be invested in drawing up the funding proposal. All proposals need to be well planned and have specific outcomes that are measurable and achievable. They should clearly demonstrate to potential funders the value of the work proposed.

Many funders, particularly statutory funders, the lottery and some trusts, use terminology in their application guidelines and/or forms that may be confusing. Ensure that you understand clearly what they are asking for; otherwise you may leave out essential data.

For a project to be attractive to funders it needs to:

- ◆ clearly meet pressing concerns
- ◆ meet a need that is not being met by any other organisation
- ◆ be cost effective as funders often look for value for money (there is often more than one way to achieve the same outcome – make sure that the outputs you are proposing are the most cost effective)
- ◆ have long-term benefits (again, this represents better value for money)
- ◆ have an appropriate exit strategy (or sustainability strategy in the case of a service, i.e. a funding strategy developed to ensure the ongoing viability of the work).

Fundraising is extremely competitive and there is no shortage of causes that are worthy of support. To increase the chances of success you need to present projects that are well conceived and thus attractive to funders.

Appendix 1: Resources

This appendix offers a list of generic resources produced by many different organisations across the UK and presents introductions to this area, practical guidance, theories and tools. This is just a small selection of the generic resources available. It also offers a list of HIV-specific resources developed for supporting infected and affected children and young people and those developed for bereaved children.

Introduction to the field

Cutler, D (2002) *Taking the Initiative: Promoting Young People's Involvement in Public Decision-making in the UK – Update*. London: Carnegie United Kingdom Trust.

Website: www.carnegie-youth.org.uk

An overview of young people's participation in decision-making in areas of national and local government, education and health.

Early Childhood Unit (2004) *Listening as a Way of Life*. London: National Children's Bureau.

This set of free fact sheets includes 'Listening to babies', 'Supporting parents and carers to listen: a guide for practitioners' and 'Listening to young disabled children'. Copies can be obtained by calling 020 7843 6064.

Willow, C (2002) *Participation in Practice: Children and Young People as Partners in Change*. London: The Children's Society.

Website: www.childrensociety.org.uk

A detailed examination of the policy context for consultation and participation with children and young people.

Active involvement of children and young people in practice development

Clark, A and Moss, P (2001) *Listening to Young Children – The Mosaic Approach*. London: National Children's Bureau.

Looks at how young children's views and experiences can become the focus for reviewing services.

Fajerman, L and Treseder, P (2004) *Children Are Service Users Too – A Guide to Consulting Children and Young People*. London: Save the Children.

Wade, H and Badham, B (2003) *Hear by Right: Standards for the Active Involvement of Young People in Democracy*. London: The National Youth Agency/Local Government Association.

Hear by Right offers tried and tested standards for organisations across the statutory and voluntary sectors to assess and improve practice and policy on the active involvement of children and young people.

Tools, toolkits and practical guidelines

Aylward, N, Jackson, C and Merton, B (2002) *The Learning Skills Council Guide to Engaging with Young People: Putting Learners in the Driving Seat*. London: The National Youth Agency for Learning and Skills Council.

Available online at www.lsc.gov.uk/news_docs/Engage_YoungPeople.pdf

Information and advice about good practice in consulting with young people aged 14 to 19, both the engaged and hard-to-reach groups.

Birth to Three Resource Guides

These guides offer support materials, resources, training materials, websites and useful contacts in relation to this group. They can be viewed and downloaded by visiting <http://www.surestart.gov.uk/communications/childcareworkers/birththreematters/training/resourceguides/>

Chambers, R (2002) *Participatory Workshops – A Source Book of 21 Sets of Ideas and Activities*. London: Earthscan Publications.

Children's Society (2002) *Young People's Charter of Participation*. London: The Children's Society.

Developed by young people and workers from the Rotherham Participation Project, this is a hands-on tool setting out principles, standards and action plans to promote the systematic participation of children and young people.

Davy, A (2002) *Can Do Play Activity Series: Serious Fun, Games for 4–9s*. London: Thomson.

This sets out games and activities to run with groups of 4–9-year-olds.

Davy, A (2002) *Can Do Play Activity Series: Serious Fun, Games for 10–14s*. London: Thomson.

This sets out games and activities to run with groups of 10–14-year-olds.

Eaton Heegaard, M (1992) *Facilitator Guide for Drawing Out Feelings*. Minneapolis, MN: Woodland Press.

This guide offers suggestions for developing grief support groups and directions for using art to help children aged 6–12 individually or in groups cope with loss and change. Curricula are provided to use with the four workbooks in the series: *When Someone Very Special Dies*, *When Something Terrible Happens*, *When Mom and Dad Separate* and *When Someone Has a Very Serious Illness*.

Hemmings, P (n.d.) *All About Me Game*. Dover: Smallwood Publishing.

All About Me was designed specifically to help children approach losses in their early years, divorce, abuse, illness and death. It consists of a colourful board game that sensitively combines the fun of a game with the needs and aims of a therapeutic relationship. For 2 to 4 players, aged 6–12. Smallwood Publishing offers a number of games to explore emotions. Visit <http://www.smallwood.co.uk>.

McCarthy, J (2004) *Enacting Participatory Development: Theatre-based Techniques*. London: Earthscan.

Contains 140 exercises designed to be used at all stages of participatory workshops, ranging from initial ice-breakers and warm-ups to exercises dealing with conflict resolution.

New South Wales Commission for Children and Young People, *Including Children and Young People*.

Information sheets available from www.kids.nsw.gov.au/info/Participation

Rogers, V (2001) *Exploring Feelings: A Resource Handbook for Work with Young People Aged 9 to 13*. Leicester: Youth Work Press.

This offers tools and techniques to engage young people in group activities that explore feelings.

Rogers, V (2001) *Let's Talk Relationships...A Handbook of Resource Activities for Young People*. Leicester: Youth Work Press.

This offers tools and techniques to engage young people in group activities that explore friendships and relationships.

Rogers, V (2003)

Icebreakers: Hot Warm-up Activities for Young People.

Icebreakers: The Good Games Book: Group Activities for Young People.

Teambuilding: Activities for Young People.

Evaluations and Endings: Activities for Reviewing Work with Young People.

Act Out! Drama and Role-play Activities for Young People. Leicester: The National Youth Agency.

This is a set of five small books that offer a range of activities, group work and team games that can be used when working with groups of young people. All activities are clearly explained and can be used separately or together.

Shepherd, C and Treseder, P (2002) *Participation – Spice It Up! Practical Tools for Engaging Children and Young People in Planning and Consultations*. London: Save the Children (Plymbridge Distributors).

Produced by Dynamix, a Swansea-based cooperative using participative methods with children and young people, this manual provides practical tools for engaging children and young people in planning and consultations.

Treseder, P (1997) *Empowering Children and Young People*. London: Save the Children (Plymbridge Distributors).

Manual full of checklists and exercises, aimed at professionals promoting children and young people's empowerment in a range of sectors.

HIV specific

The following resources and research have all been made specifically to illustrate, address and support the needs of children and young people living with and affected by HIV. Please note the date of publication as this could mean that certain statistical information, or references to services are out of date, although the body of the resource is still relevant.

Barnardo's (1997) *Activity Pack: A Resource Pack for those Working with Children Affected by Parental Illness*. London: Barnardo's.

This pack aims to help children affected by parental illness better understand their situation and to help parents/carers tell children more about their situation. The pack contains activities that explore the family, illness, their feelings and changes. To order, visit Barnardo's publications shop at <http://www.barnardos.org.uk/shop/publications/acatalog/>

Body & Soul (1998) *Spirit of Youth*.

This film takes you on a journey with a group of young people infected and affected by HIV.

It can be used by primary and secondary schools as it includes lesson activities, games and information. Visit <http://www.bodyandsoulcharity.org/>

Conway, M (2003) *Will Someone Listen? Meeting the Needs of Children and Young People Living with HIV*. London: National Children's Bureau.

This report presents the findings from national seminars on the issues facing children and young people infected with and affected by HIV. To order a copy visit <http://www.ncb.org.uk/hiv/>

CWAC (1996) *Problem?* London: CWAC.

An excellent short video aimed at 7–10-year-olds that explores the social issues involved in living with HIV, including isolation and stigma. Visit <http://www.cwac.org/pages/english/publications.html>

CWAC (1998) *The Cloakroom*. London: CWAC.

A video and information pack aimed at 13–16-year-olds, this resource focuses on secrets around illness and HIV. Visit <http://www.cwac.org/pages/english/publications.html>

CWAC (2000) *HIV Risky Business*. London: CWAC.

A short video aimed at 12–15-year-olds that presents a clear and simple safer-sex-and-drugs message. This video separates fact from fallacy and teaches young people how to protect themselves. Visit

<http://www.cwac.org/pages/english/publications.html>

CWAC (2004) *Voices of Young People*. London: CWAC.

The booklet, following on from *Voices of Children* has been compiled from a range of materials in which young people living in the UK have described their experiences of living with HIV. Visit

<http://www.cwac.org/pages/english/publications.html>

CWAC (2005) *Talking with Children*. London: CWAC.

This is a booklet targeted at parents/carers that suggests practical ideas on how to talk to children about illness and HIV. It includes both infected and affected children. Visit <http://www.cwac.org/pages/english/publications.html>

Lewis, E (2001) *Getting Help – A Support Pack for Families Living with HIV*.

London: National Children's Bureau.

This pack contains two information guides, one for parents/carers and the other for young people, based on the findings of Elizabeth Lewis's research *Afraid to Say?* To order a copy visit <http://www.ncb.org.uk/hiv/>

Miah, J (2004) *Talking with Children, Young People and Families about Chronic Illness and Living with HIV*. London: National Children's Bureau.

The London Consortium of Paediatric Clinical Psychologists, Body & Soul and the Children and Young People HIV Network produced this report. It explores the issues faced by practitioners and families on talking about HIV infection to either an HIV positive child or a child with an HIV positive family member. To order a copy visit <http://www.ncb.org.uk/hiv/>

Waterhouse, L (2004) *Soul Love*. London: Piccadilly Press.

This fictional paperback, aimed at 10–15 year olds, presents information about HIV and issues for young people living with the virus in the context of a teen love story in rural England.

St George's Paediatric HIV Team (2003) *Where Do I Start? Talking to Children with HIV about their Illness*. London: St George's Paediatric HIV Team.

This booklet is for people who care for children with HIV. It sets out to answer questions and alleviate fears that many parents and carers have. Copies can be

downloaded from the CHIVA website (<http://www.bhiva.org/chiva/index.html>) under the section 'Articles and Protocols'.

Research

Chinouya, M and O'Keefe, E (2004) *Young African Londoners Affected by HIV: Making Sense of Rights*. London: The Nuffield Trust.

Lewis, E (2001) *Afraid to Say? The Needs and Views of Young People Living with HIV/AIDS*. London: National Children's Bureau.

This research was conducted with children aged between 6 and 14, all of whom are either infected with or affected by HIV. It presents these children's views on what it is like to live with HIV in all areas of their lives, including school, building friendships, play and bullying.

Bereavement

The following resources have been specifically developed to offer practical help for children who have suffered a bereavement.

Childhood Bereavement Network, NCB (2002) *A Death in the Lives of...* A video with a group of 13–16-year-olds talking about the support they received through their experience of bereavement.

Visit www.ncb.org.uk/cbn

Childhood Bereavement Network, NCB (2002) *You'll Always Remember Them, Even When You're Old*. A video with a group of 6–12-year-olds talking about their experience of being bereaved of a parent/carer.

Visit www.ncb.org.uk/cbn

Childhood Bereavement Network (2005) *I Can, You Can*. Set of four postcards for bereaved children and young people to use as prompts for support from their parents/carers, teacher and friend, and to remind themselves of what can help.

Visit <http://www.ncb.org.uk/resources/>

Leeds Animation Workshop (2002) *Grief in the Family*. This 14-minute animated video looks at the ways children and young people respond to grief, and what the adults around them can do to help. It gives parents/carers and carers an insight into the process of grieving, its physical and emotional effects, and the special needs of children and young people. A video, *Not Too Young to Grieve*, which explores supporting bereaved children under the age of 5, is in the process of being produced.

Visit <http://www.leedsanimation.demon.co.uk/films/grief.html>

Ribbens McCarthy, J with Jessop, J (2005) *Young People, Bereavement and Loss: Disruptive Transitions?* Published by the National Children's Bureau for the Joseph Rowntree Foundation.

This is a wide-ranging review of the literature on young people, bereavement and loss.

Visit <http://www.ncb.org.uk/resources/>

Appendix 2: Useful information

Statistics

Listed here are organisations that gather current data about children and young people living with HIV. Please note that some of the data presented is cumulative, in that it gives the total figure to date of children who have tested positive for HIV since data was first collected.

AVERT presents accumulative data of both national and global figures. The organisation also offers stories, quizzes and additional information that may be useful in designing sessions. Visit <http://www.avert.org.uk/>

The Collaborative HIV Paediatric Study (CHIPS) aims to collect more detailed clinical, laboratory and treatment information on all HIV-1 infected children under follow-up at centres participating in PENTA (Paediatric European Network for the Treatment of AIDS) trials since 1 January 1996.

Health Protection Agency collects quarterly data on the number of people living with HIV. They can provide, on request, more specific information on regional data. Visit www.hpa.org.uk/cdr/

The National Study of HIV in Pregnancy and Childhood (NSHPC) collects data through confidential obstetric and paediatric reporting systems and produces a quarterly newsletter with regularly updated tables. For more information and to receive the newsletter email: nshpc@ich.ucl.ac.uk

National children's HIV organisations

Children and Young People HIV Network works nationally to bring together organisations concerned with children, young people and HIV/AIDS. The Network aims to be an effective voice for children and young people living with and affected by HIV in policy and practice development, and to challenge stigma and discrimination.

National Children's Bureau

8 Wakley Street

London

EC1V 7QE

Tel: 020 7843 1911 | Email: mconway@ncb.org.uk | <http://www.ncb.org.uk/HIV/>

The Children's HIV Association (CHIVA) is an association of professionals committed to providing excellence in the care of children infected or affected by HIV and their families. Membership includes practitioners from nursing, GU Medicine, paediatrics, community child health, child development, psychology, social work, dieticians, pharmacists and support services.

For more information, visit <http://www.bhiva.org/chiva>

Children with AIDS Charity (CWAC) was set up to help the youngest of those infected with or affected by HIV and AIDS to maintain a good quality of life. It is a national UK charity with the aim of working towards a future without prejudice for these children and their families.

Children With AIDS Charity

Lion House

3 Plough Yard

London

EC2A 3LP

Tel: 020 7247 9115 | Email: info@cwac.org | <http://www.cwac.org/>

National HIV organisations

African HIV Policy Network (AHPN) is an umbrella organisation which represents African community groups addressing HIV/AIDS and sexual health throughout the UK.

AHPN

New City Cloisters

96 Old Street

London

EC1V 9FR

Tel: 020 7017 8912 | Email: info@ahpn.org | <http://www.ahpn.org>

Crusaid exists to make a difference to people living with and affected by HIV and AIDS. Crusaid relieves poverty and illness caused by the virus, educates, and supports vaccine research through independent fundraising and grant-making.

Crusaid

1–5 Curtain Road

London

EC2A 3JX

Tel: 020 7539 3880 | Email: office@crusaid.org.uk | <http://www.crusaid.org.uk>

National Aids Trust (NAT) is the UK's leading independent policy and campaigning voice on HIV and AIDS. NAT develops policies and campaigns to halt the spread of HIV and AIDS, and improve the quality of life of people affected by HIV, both in the UK and internationally.

NAT

New City Cloisters

196 Old Street

London

EC1V 9FR

Tel: 020 7814 6767 | Email: info@nat.org.uk | <http://www.nat.org.uk/>

Positively Women is the only national charity working to improve the quality of life of women and families affected by HIV; providing specialist support by women living with HIV; enabling women to make informed choices and challenging stigma and discrimination.

Positively Women

347–9 City Road

London

EC1V 1LR

Tel: 020 7713 0444 | <http://www.positivelywomen.org.uk/>

Terrence Higgins Trust (THT) is the leading HIV and AIDS charity in the UK and the largest in Europe. It has national and regional offices across the UK, offering a range of services and information.

THT (National Office)

52–4 Gray's Inn Road

London

WC1X 8JU

Tel: 020 7831 0330 | Email: infor@tht.org.uk | <http://www.tht.org.uk/>

UK Coalition of People Living with HIV and AIDS is an organisation committed to enabling the diverse voices of people living with HIV and AIDS to be heard with a view to influencing change.

UK Coalition

250 Kennington Lane

London

SE11 5RD

Tel: 020 7564 2180 | Email: reception@ukcoalition.org |

<http://www.ukcoalition.org/>

References

- CWAC *Voices of Children*. London: CWAC.
- CWAC (2004) *Voices of Young People*. London: CWAC.
- DfES (2005) *Managing Medicines in Schools and Early Years Settings, March*. London: DfES. Available online (consulted October 2005):
<http://publications.teachernet.gov.uk/eOrderingDownload/1448-2005DCL-ENV3final.pdf>
- Great Ormond Street NHS Trust (n.d.) 'Health questionnaire for those working with immune compromised children and young people'. London.
- Health Through Action (2003) *The Affected Child* (set of 6 postcards). London: Barnardo's.
- Health Through Action Project (2004) 'Yo Dude' (project leaflet). London: Barnardo's.
- Karibu (2004) Consultation with young people at Karibu.
- Lewis, E (2001) *Afraid to Say? The Needs and Views of Young People Living with HIV/AIDS*. London: National Children's Bureau.
- Miah, J (ed.) (2004) *Talking with Children, Young People and Families about Chronic Illness and Living with HIV*. London: National Children's Bureau.
- NCB (2005) *HIV in Schools*. London: National Children's Bureau.
- Penny, C (ed.) (1999) *Talking with Children about Illness and HIV*. London: CWAC.
- Positive Vibes (2004) *The Newham Consultation: Children and Families living with or affected by HIV/AIDS*. London: Barnardo's
- St George's Paediatric HIV Team (2003) *Where Do I Start? Talking to Children with HIV about their Illness*. London: St George's Paediatric HIV Team.

