

Talking with Children, Young People and Families about Chronic Illness and Living with HIV

Edited by Jennifa Miah

Contributions by:

BODY & SOUL

Health Initiatives
for Youth: UK

The Children and Young
People HIV Network, NCB

The London HIV Paediatric
Psychology Forum

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"Be the change you wish to see in the world."

GHANDI

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Foreword

There are approximately 50,000 people living with HIV in the United Kingdom and it is estimated that one third of these people are unaware of their status. Sixty-one percent of all new HIV infections in the United Kingdom were heterosexually contracted. SOPHID figures for 2002 estimate that there are approximately 1085 children and young people living with HIV in the United Kingdom. Although the number of children living in a family where there is an HIV infection is unknown, estimates drawn from previous data and HIV prevalence suggest at least 20,000. Britain has one of the highest rates of teenage pregnancy in Europe and this is also likely to lead to an increase in the number of young people diagnosed with HIV, who may have sexually contracted the illness. The provision of services to children, young people and adults living with HIV is now developing within a network model across the United Kingdom to address the changing demographics and epidemiology of this group. Professionals in areas with low prevalence rates, developing local services for small numbers of children diagnosed with HIV, often seek advice and guidance about good practice in relation to talking about HIV and disclosure of diagnosis.

We would encourage the Government to advocate more, and pursue policies to improve the lives of children and young people living with HIV. We recognise that they have brought forward significant measures to boost key services for children in health and appear committed to ensuring all children and young people have access to high quality health and social care through the National Service Framework for Children (2004). Government Departments need to involve children and young people in the development of policies and services more. I hope that this piece of work encourages dialogue and leads to changes in policy, which improve the quality of life for children and young people living with HIV.



Neil Gerrard MP
Chair of the All-Party Parliamentary Group on AIDS

Introduction

This document draws together evidence based practice and practice based evidence from clinical experience and understanding that has developed on the issue of talking with families about illness and HIV. It proposes a number of good practice principles of engaging parents in a dialogue about talking to children about HIV. The purpose of the report is to support professionals in thinking and talking to children and young people. For experienced colleagues working in well-resourced hospital or community based services it might serve as a confirmation of well-established ways of working. For those new to the field it might present as useful guidance.

Section One provides a psychological framework for communicating with children about health and illness. It focuses on supporting professionals to talk to families about how to cope with managing the process of disclosure of a medical diagnosis. It aims to promote principles of good practice that encourage talking openly, whilst acknowledging the reality of the wider context and the ongoing need to tackle the discrimination associated with racism and stigma.

Section Two discusses disclosure issues in a community setting. BODY & SOUL describe the range of services they offer to children, young people and parents to support them with the process of disclosure. This section focuses on promoting good practice within a community setting and highlights strategies that can be used to support individual members of a family in coping with this process. It highlights the views of young people using their service.

Section Three provides an overview of the issues for young gay people. It recognises the importance of providing integrated services but highlights the need to ensure these are accessible and equipped to address the needs of all young people using them. This is the shortest of all the sections and this reflects the lack of service provision available to this group of young people. The Elton John AIDS Foundation has published a report, 'Sexual Exclusion: Homophobia and Health Inequalities' (2004), which provides a more comprehensive review of the issues for young gay, lesbian, bisexual and transsexual people. We hope that their recommendations will then be reflected in future service development.

Section Four focuses on issues for affected children and young people who are often marginalised groups. It highlights the views of affected young people from the Karibu Project who attended a workshop on talking about HIV and disclosure. It also presents a framework for involving children and young people in policy and practice development.

A range of views were expressed by young people about where they thought the 'best' place to be 'told' was and even how they would like to be 'told'. The diversity of views reflects the heterogeneity of this group of young people rather than being contradictory. Moreover, all the young people that contributed to this report unanimously agreed that they did wish to be trusted and 'told' about both their own and their parents' health status so that they could support each other.

Use of words

For ease of reading the word parent has been used throughout the document to refer to an adult in a parental or caring role in relation to the child/young person. It is not intended to refer exclusively to those with a biological relationship with the child.

Guidance for Clinicians in the NHS

Jennifa Miah, Sarah Waugh and Alex Divac

1.0 UK Context

The provision of services for children with HIV is now developing within a network model¹ across the UK. Shared care provision between local and specialist centres means that children can be seen locally, with review by multi-disciplinary specialist teams at lead centres. Health professionals developing services for small numbers of children diagnosed with HIV often seek advice and guidance about good practice in relation to talking about HIV and diagnosis disclosure.

The Children's National Service Frameworks set out national standards for improving quality of care across health and social services. It puts children and young people at the centre of care by building services around their needs and promoting their voices².

The prevailing view of good practice within the UK is that information about illness should be shared with children at an appropriate developmental level. The principle of openness is informed by: existing good practice in paediatric conditions^{3,4,5,6}; documents^{7,8,9,10}; and practice based evidence^{11,12,13,14}.

Clinical experience in the UK has been developed in working with particular groups and caution should be used in applying the ideas presented here in different settings with different populations. However, they may be adapted to 'fit' with the specific social, cultural, religious and health service context in which the families are offered treatment. The authors of this consultation document are clinical psychologists working within a range of HIV specialist service frameworks in London spanning paediatric (St George's Hospital, Great Ormond St Hospital) and family orientated (Newham General Hospital) service models. They also span inpatient, outpatient and community settings.

Treatment centres may wish to consider the importance of health care professionals having access to psychologists for regular consultation sessions to review and support the process of HIV diagnosis disclosure. They can also raise concerns for families that are dealing with particularly complex issues, where referral to clinical psychology may be appropriate e.g. backgrounds of multiple trauma, multiple losses.

1.1 Principles of Good Practice

Partnership

Working in partnership with families is fundamental in effective communication and the basis of good practice.

Voice of the Child

It is important for health care providers to be aware of the marginalized position of children and young people. The rights of children and young people should be respected by making space for their voices.

Cultural Competence

Clinicians who root their practice in a culturally competent framework¹⁵ are most likely to achieve good outcomes when working with families with HIV.

Interagency Working

It is good practice to liaise with organisations in the voluntary sector that play an important role in offering support to families around the process of disclosure in the community setting.

1.2 What makes HIV Different from other Life Limiting/Chronic Health Conditions?

1.2.1 Social and Cultural Context

The populations of children, young people and families living with HIV in the UK originate primarily from various parts of Sub-Saharan Africa although not exclusively¹⁶. They do not constitute a homogenous group, but instead include families from diverse cultural, religious and social backgrounds. Some are part of a larger asylum seeking and refugee community.

1.2.2 Stigma, Confidentiality and Discrimination

As HIV remains a stigmatising condition, the whole family may find itself cut off by enforced secrecy from community supports and rituals, religious groups, kin and friendship networks that are necessary for its continued functioning and would enhance the well being and mitigate the pain. Most parents are concerned that the child/young person may unintentionally break the silence about HIV. They fear that by sharing the knowledge of diagnosis with others, children may risk rejection and discrimination.

1.2.3 Family Context

The implications of receiving a HIV positive diagnosis are often complex, multiple and trans-generational. The majority of children with HIV have been infected vertically and where this is the case, talking about illness and HIV presents parents with the challenge of double disclosure i.e. the task of disclosing both their own and their child's diagnosis. Parents may find it difficult to discuss their own diagnosis because they may be adjusting themselves or frightened of rejection, or fearful of stigma or they may simply wish to protect their child from what they perceive to be distressing information.

1.3 Developmental Understanding of Illness

Children's understanding of illness undergoes developmental changes that are not only age related but influenced by other factors. An appreciation of these changes provides a basis for communication with children and is particularly relevant when difficult and sensitive topics are discussed.

Pre-school and Infant Children (two–seven years)

Very young children hold beliefs about illness, which are superstitious, circular and non-differentiated, for example, “you get cold from kissing old ladies.” They are likely to understand explanations such as “there are goodies and baddies in the blood”.

Primary School Children (seven–eleven years)

As they get older, children’s reasoning becomes more specific. They start to acknowledge a limited number of causal factors in precipitating different illnesses. An example of a simple explanation they might understand would be “germs cause colds”.

Secondary (eleven years onwards)

As children move towards adolescence, understanding of illness is enhanced by formal biological education, so causation of illness is understood in biological terms. Their level of understanding could extend to the functioning of the immune system, transmission route, life style and health links.

However, there is ample evidence both from research and from clinical practice that experience of illness plays a significant role in enhancing children’s knowledge and understanding of that particular condition. For example, children as young as four years old understand the concept of illness and death in accordance with their developmental level and illness experience^{17,18}.

1.4 The Process of Talking about HIV with Children, Young People and Families

Talking with children about their condition and telling them about their diagnosis is an ongoing process. It starts with simple explanations, which are built upon with increasing complexity and sophistication. The rate at which information is shared depends on a range of factors, including the child’s age, maturational level as well as medical, family and social issues. There are specific events which punctuate the process, such as naming HIV, which carry particular significance. Giving the diagnosis is not an end point, but a starting point for continuing discussion about HIV and its implications.

Clinicians should work in partnership with families to identify what kind of support is required and agree a shared plan of how this will be provided. This will involve thinking about how to unpack what is known and what is not known. For example, children may pick up bits of information or misinformation from friends, TV and even clinic visits or community groups they attend. It will also include who should do the telling or naming and at which stages. Some parents prefer to undertake the task themselves whilst others prefer professionals to undertake this task either with them or on their behalf.

Responsibility for initiating the conversation about what children need to know about their condition sometimes lies with professionals. For the purposes of clarity, while risking simplification, the proposed framework highlights elements of the process. These should not be seen as stages, which need be followed sequentially; in reality, a host of factors influence the order in which each phase occurs.

1.4.1 Facilitating Communication

While exploring family's views and cultural beliefs about open communication (for example, "What do you believe is important for the child to know about clinic visits?") professionals are advocating that all children need to be given developmentally appropriate explanation for events like clinic visits, blood being taken, medication.

Early discussions about confidentiality and about whom else needs to know about the HIV diagnosis provide a basis for communication about sharing information, which will be returned to in time and as circumstances change.

1.4.2 Building Information Blocks

The child's knowledge and understanding needs to be built upon with the addition of new information as appropriate. Brief educational sessions for children and parents can be built into clinic or home visits. For example, basic information on blood and the immune system; viruses in the blood; basic knowledge of interaction between medication and immune cells etc.

Including parents in these session means that they can continue to support the child's learning and understanding.

1.4.3 Naming Event

Generally, naming of the HIV condition is considered around the age of 12 years. However, it may happen earlier or sometimes later, when there is lack of family support or the child is developmentally immature. It is good practice to consult parents about their preferred way of sharing the name of the condition with the child: with or without the support of the professional.

1.4.4 Re-visiting and Disclosure of Parental Diagnosis

This refers to follow up conversations with both parent and child, which review the child/young person's understanding and explore the emotional impact of the naming event on the child/young person. Information usually needs to be given and discussed more than once. Separate conversations with the parent may be necessary to discuss:

- their support needs and how they are coping with managing the process of disclosure of the child's diagnosis
- how to manage disclosure of their own diagnosis.

It is also important to identify opportunities for parents to access peer support from people in similar situations. This is likely to be accessed through organisations in the voluntary sector.

1.4.5 Telling Family and Friends

Exploring the young person's views, beliefs and feelings about the dilemma of sharing with other relevant family members and friends is an ongoing task. It is very important that a professional takes a neutral position in relation to self-disclosure and facilitates the exploration of fears, hopes and ways of managing stigma.

1.4.6 Telling the Wider Network

Sharing information with a wider system is the focus of this step and this may include, for example, other health professionals, social services or education authorities.

While informing parents that there is no legal obligation to share a child's diagnosis, professionals should also invite them to consider the possible pros and cons of sharing the information about HIV with, for example, a school nurse or a head-teacher.

For many parents preserving confidentiality outweighs the potential benefits of wider disclosure. They may choose to share some, if not all, of the information about the child's condition. For example, those who prefer not to tell the child's school the HIV diagnosis may give information about the child having a chronic condition, which requires regular review. This offers the school a reason for frequent absences, and gives them an opportunity to better understand the needs of the child.

Sharing information both within and outside the immediate circle of family and friends needs careful consideration. Amongst other things, parents and professionals need to consider how the child may feel when they become aware that the wider network knew the diagnosis before they did. This may infringe the young person's right to choose how and with whom to share personal and health information.

1.4.7 Repeated Re-visiting

There needs to be repeated discussion and opportunities to consider the full meaning of living with illness and the implications of the diagnosis. Having a full grasp of the meaning and implications of the HIV diagnosis is unlikely even for young people who have been aware of their diagnosis for a while. Parents and young people often need opportunities to re-visit different ways of managing the condition and the fit (or lack of it) between coping strategies suggested and challenges faced at different life stages.

1.5 Issues for Young People when the Mode of Transmission is Sexual

Adolescence is a transitional stage and it is extremely important to make space for both the adult and the child. London services based at St Mary's Hospital, Great Ormond St Hospital, St George's Hospital and Newham General Hospital have either developed or are in the process of developing youth clinics. For example, Mortimer Market Sexual Health Team run TEAM Clinic and the Sun Clinic team, based at Newham General Hospital, are holding a consultation day with young people to involve them in developing the adolescent clinic. This is to ensure that service providers are informed about the needs of young people and that they have a role in shaping the service provided to them.

1.5.1 The Process of Disclosure

The process of disclosure in this context may involve some of the elements previously discussed. However, there may also be other issues that need consideration such as, sexual health and disclosure in the context of intimate and/or peer relationships. Young people may need support on developing confidence in building relationships, negotiating safer sex and parenting. Additional support is necessary for younger mothers who are diagnosed via antenatal services.

They often require linking into generic services e.g. teenage pregnancy teams, as well as specialist HIV teams.

Some young people have histories of multiple trauma, rape or torture involving gang rape. Such horrendous experiences can have a significant negative impact on a young person in terms of poor self-image, lack of confidence, low self-esteem, and on their ability to trust others and sometimes their ability to protect themselves. Young people who have histories of torture involving gang rape, which they identify as the mode of transmission of HIV, are particularly vulnerable. They often report on feeling re-traumatized when they receive the medical diagnosis because of the association with the assault. It is important to ensure that they have access to specialist psychological support and co-ordinated packages of care, as well as access to community support networks.

This group of young people sometimes find it difficult to engage in services because they find it difficult to trust in people or the world around them. They sometimes do not wish to access community-based support networks because of feelings of alienation, humiliation and shame associated with the trauma that took place¹⁹. Community based support networks provide an essential safe space and normalising experience for many young people. Clearly, there is nothing normal about organised violence or sexual violation of young people. Young people who have had such experiences often need specialist support to deal with the psychological consequences including the impact it has on their sense of self, sense of safety in the world, the process of adjustment and the process of disclosure.

1.6 Concluding Comments

Many of you may be familiar with the dilemma of managing the tension between promoting principles of good practice that focus on talking openly whilst acknowledging the reality of the wider context and the need to tackle discrimination associated with racism and stigma. Clinicians may also be confronted with the challenge of dealing with an array of human rights issues e.g. families fleeing persecution and trauma in their country of origin as well as post-arrival experiences of trauma in the UK.

There is a range of complex issues that need consideration when talking with children, young people and families about illness and HIV. There may be multiple contexts that inform when, how or whether a parent feels comfortable to begin the process of talking about illness and HIV. Different levels of support may be required for different families. There is a wide range of strategies that can be adapted to 'fit' with the specific needs of different families and professionals need to work in close collaboration with the individual, their family and friends as well as the wider network.

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2.0 BODY & SOUL

We provide a safe, confidential and supportive environment for children, teenagers, women, heterosexual men and their families living with or closely affected by HIV/AIDS. Emotional, physical, social and welfare needs are met through our holistic services and structured group support sessions where clients are able to meet others affected by HIV/AIDS, exchanging vital support and information. This is often the start of a journey to change the devastation of an HIV diagnosis into positive strategies to manage the impact of HIV.

During the last 10 years, with the introduction of anti-retroviral treatments, the needs for those living with HIV have changed considerably. Life expectancy has increased and long term, consistent support is what clients need in order to come to terms with living with HIV. We address these needs by providing a solid, on-going service, offering support for the whole family. Children and young people are able to access under 19's services independently of a parent.

Through working closely with the whole family, complex, life-changing issues such as disclosure can be addressed and processed in a planned manner. This ensures the disclosure can be as positive as possible.

Throughout the disclosure process, BODY & SOUL is committed to strong partnership work, striving to ensure all agencies are working holistically together in the provision of support for the client.

2.1 Disclosure Issues

In our experience, disclosing has predominantly been a positive decision. It is important wherever possible to build up a relationship with the parent prior to the 'naming event' so that there is an agreed plan to ensure they feel confident and comfortable with the process leading up to the actual disclosure of HIV. Where this has not been the case and communication with professionals is not in place, negative disclosures can occur. These are often unplanned or unintentional. Examples include a parent saying "you have HIV" and a health professional accidentally saying to the young person during monthly blood tests that they have HIV. In both cases, the young person was left with no full explanation and left with mixed knowledge and understanding. They reacted negatively, one becoming very disruptive at school and the other refusing medication and becoming withdrawn.

Those living with HIV face many other challenges in their everyday lives and disclosure must take place in the context of the individual family, for example, those with siblings who don't know, those in care, orphans/unaccompanied minors, those on medication from very young age and those who have experienced great loss in their lives. With the Government's new legislation on immigration, dispersal is having a profound effect on those disclosed to. They are dispersed out

of London to areas where there are generally no services in place. With no structured support, it often marks the beginning of a downward spiral of depression through isolation and despair.

The experiences fed back to us from children, teenagers and adults have over-riding common themes: disclosure is extremely individual; different levels of support are required and each family is unique.

2.2 Principles of Good Practice

Good practice of disclosure has to be flexible, and you have to work within the presenting context, there is no single model that can just be followed.

It is important to work with the family at a pace they are comfortable with, and that they are informed of the support in place for the parent and child/teenager.

Ensuring that all age groups receive support enables disclosure to take place gradually. This can involve providing advice to the parent on giving a child small pieces of information over time, leaving leaflets around for them to read, and encouraging them to watch programmes. This can lead to them developing a basic understanding, or at least awareness of, illness and HIV/AIDS.

Experience and positive feedback has shown that when a child is able to access our children's service and/or the BaSe group prior to 'the naming event', it significantly eases the distress associated with the disclosure process. This highlights the importance of access to peer support.

BODY & SOUL is committed to working in partnership and this has been crucial in successful disclosures. Clear consistent communication with other health professionals, clinicians, foster carers and social workers who are involved with the family, is essential in order to ensure the disclosure is a positive experience.

2.3 Disclosure and the Support Needs of Parents

Through accessing adult support sessions, parents are enabled to talk to their peers about disclosure, they can hear others share their experiences and ask questions. At Body and Soul teenagers have facilitated adult workshops on disclosure, sharing openly with parents issues such as when they ideally would like to have been told, by whom and where. These workshops have been extremely successful and have also provided a forum for the young people to put forward issues on why they believe they should be disclosed to. These included having a sense of control, preventing feelings of isolation if not informed, helping them make informed decisions and explaining confusing or disturbing events.

Through these different opportunities, parents considering disclosures are able to build up confidence and knowledge of how they would feel comfortable doing it. In addition to this, with the constant support and advice from the staff, parents can work through complex issues around disclosure. These can include, when is the best age to tell, being afraid that the child will tell others, wondering "Will they blame me?"

One of the most frequently asked questions is, at what age do I disclose? We believe that at the age of 13, children/young people have a right to know. This is an age when they are becoming young adults and when they have many questions. However, we work very closely on the best age to disclose as there are many variable factors, including: the child's maturity, if they start to refuse medication, changes in their behaviour or performance at school, if they begin to ask questions, or poor health/ social issues.

2.4 Supporting Parents with the Process of Disclosure

Preparation directly before the 'naming event' with parents allows them space to go through issues that could include the following:

- What are your reasons for wanting to tell your children?
- What are your reasons for not wanting to tell your children?
- Would you like anyone else present e.g. family/friend?
- Who would make you and young person feel comfortable?
- What are their hopes and fears/ expectations and anxieties?
- What questions might your child ask?
- What they think the young person may understand.
- Who can the child talk to? Who knows, if anybody?

This preparation enables the parent to feel as comfortable as possible as they have had time to think through the issues and are clear of the process, hence ensuring the 'naming event' is personal to their needs.

Decisions regarding who is actually going to tell the child/young person need to be made at the onset. Feedback shows that children/young people prefer the parent telling them rather than a professional, as this makes them feel respected, trusted and loved. However, experience has shown us that sometimes it may be too painful and emotional for the parent. BODY & SOUL can interject and support both the parent and child/young person. It is important to highlight that everyone involved needs to be flexible and prepared for different reactions. There can be outbursts of anger, complete silence, and any person walking out.

Many adults often report on experiencing very mixed feelings after the 'naming event'. Feelings of relief as if a heavy burden has been lifted combined with feelings of fear and anxiety, which can be accentuated depending on the reaction from the child. We encourage them to continue accessing the adult services where they can continue to have a space to talk openly, ask for advice if they are being confronted with challenging questions from their child e.g. Why did you not tell me till now? How did I get it? How come my brother does not have it? They also have the option to access counselling and complementary therapies to ease stress levels. For those who do not feel ready to access the peer support, telephone support is continually offered, in which advice and information can be given at any time.

2.5 Supporting Parents and Children with the Process of Disclosure

Once disclosure has taken place, it is essential that both child and parent be given ongoing future support. No one can determine how either party will act following disclosure and it is important that they know there is support no matter how they react. Feelings of anger, depression, fear, rejection, guilt and injustice are examples of coping and trying to come to terms with the disclosure.

For the child/young person, many questions and feelings will need to be taken into consideration. Young people react individually. They may withdraw into themselves, become aggressive and frustrated, or refuse to take their medication. If they have been the primary carer for the family and cared for an ill parent and watched their health deteriorate before dying, knowing that they are also living with HIV can bring out immense feelings of fear of the same things happening to them.

2.6 Supporting Children and Young People Living with HIV

"Before I came to TEEN SPIRIT I was very alone, I had no one to talk to and I felt my life was going to end. Coming here has meant I have been able to talk to people my own age and learn all about HIV. I'm getting more confident and I am beginning to learn to cope." Alice aged 16 HIV+

Children aged under nine can access our children's centre services; children are able to build secure friendship support networks, confidence and self-esteem. Once they move to the BaSe group for 10–12 year olds, they additionally take part in structured workshops focussed on issues that will later be faced within the process of disclosure.

BODY & SOUL facilitates two groups for children and young people who have been disclosed to, the positive monthly group for 10–12 year olds and TEEN SPIRIT a group for 13–19 year olds. They offer a safe confidential space for children/young people to talk openly about being affected with HIV/AIDS. Through structured workshops on challenging issues including: how HIV impacts on the body, bereavement, adhering to medication, coping with stigma and prejudice, living a double life, disclosure and isolation, the young people can learn to begin to come to terms with their status.

Both groups cover work on being an adolescent; starting relationships, respect, keeping healthy, dealing with bullying and conflict. The groups allow the young people to share experiences with their peers and talk about how they are coping. Through this and the workshops, the young people can build their self-esteem and identity and grow in confidence in order to develop positive strategies to manage HIV in their lives and begin look to the future.

Building self-esteem, self-identity and confidence helps to contribute to beginning to learn to live with HIV. For both the parent and young person, gaining these empowering skills are even more important once the 'naming event' as taken place. Within the services for both adults and children/young people at BODY & SOUL, there are opportunities to volunteer. This in turn equips clients with new experiences/skills and knowledge that, if they choose, they can use for furthering their own careers or job opportunities.

2.7 Promoting the Voice of Children and Young People

The views of children and young people living with, or affected by, HIV are paramount in influencing and directing the process of disclosure.

At TEEN SPIRIT we have been involved in different workshops to share how we as young people have felt in relation to our experiences, positive and negative. Below are some of the views of TEEN SPIRIT members from a workshop we held over the summer holidays.

2.7.1 “Why is it important to know?”

Young people felt that they had the right to know about their health, and what was happening to their bodies. They wanted honesty:

“I think for a child/teenager who is HIV+, and having to take all the medications for the rest of their lives, they need to be enlightened and told the truth, because what is the point of taking all these tablets if they do not know the true reasons.”

“As a young person living with HIV, I feel it is my information and I should be the one to know what is happening to me, and deciding what I want to do.”

“Children should be respected as any other human being and they have the right to know truthful answers.”

2.7.2 “Where would we like to be told?”

The group all agreed that disclosure had to take place in a safe space, in which they felt comfortable:

“The hospital may not be a safe environment to disclose, it would be better at home where parents and the child/teenager feel more comfortable and where they can show their emotions.”

“The place is important, as when I found out, I just wanted to hit out and get away from everyone, especially my family.”

2.7.3 “Who should do the telling?”

The young people had a range of views on who they wanted to be told by, however, trust plays an important role in planning who discloses:

“In my opinion on who should tell a child/teenager about their HIV+ status is that it should be a parent, because then they will feel more comfortable and loved. Also they would have a strong relationship which would be based on trust and support.”

“As a young person, you may not feel that someone who is paid to do a job cares about you in the same way that a family member does – this might affect how you deal with the disclosure.”

“Not everyone has parents, it is important that it is someone you completely trust, someone you can be yourself with, coz you never know how you will react. I just wanted comfort and to know that I was not on my own.”

2.7.4 “When should we be told?”

The group felt that the process of disclosure should start long before the naming event:

“I think children can be told about HIV in a way they can understand. Also, if they are informed with the correct knowledge about HIV, it will take away the fear that surrounds HIV as they grow older.”

“I was told about my dad’s HIV status straight after my mum died. It was really hard to take in at that time. I believe parents should tell their children before anything serious happens and before it is too late.”

“I would have liked my father to have told me the truth about what was going on whilst he was still alive. Even though I was young, I knew he was very ill. At the time, I felt totally helpless, which hurt me even more as I wanted to help my father in any way I could to prolong his life or for me to feel that I did help my father in his last days.”

“Parents should be given space to come to terms with their own diagnoses first.”

“Support networks should be in place before disclosing to a child/teenager.”

2.7.5 “How should we be told?”

The young people recognised the different needs of the individual, based on understanding, age, maturity, experience, situation etc:

“You should consider the child’s level of understanding and present the information to them in simple terms; often parents underestimate their child’s ability to deal with this type of information.”

“Disclosure is not a one-off moment, it happens over time and information should be given gradually in relation to their age.”

“I was told by my sister in a really informal way, I wish it had been done in a more structured way and not just a conversation, as if it wasn’t really important.”

“I feel young people need to be given more information, when I was told I was HIV+, that was it, I was never told anything else. Mum and me never spoke about it again. I was so scared.”

2.8 Personal Perspective of a Young Person

“When I was told about my mum’s HIV status, I was in denial. Months went by and I saw how my mum was living with HIV and taking medication. It had hit me she was going to die, not now, but sooner than I was prepared for. I blamed myself – I thought it was bad karma in my past life. The day I went to TEEN SPIRIT to meet other people going through the same thing as I was. I thought everyone there would be a mental case, but it felt safe, normal, a place where at last I could just be me – no more lying.”

2.9 Concluding Comments

Disclosure is not a process for which set guidelines can be produced. We have shared with you an outline of how disclosure can take place and ways to assist children and young people to have as positive an experience as possible.

Discussions on 'need to know versus right to know' will continue for many a year, but what we have to do is listen to the voices of the children/young people.

Disclosure has to be flexible and is unique to each individual. A holistic approach is needed, the young person, their family, the current circumstances and so on all need to be taken into account.

Working with the whole family, children/teenagers and parents alongside professionals involved, is central to the disclosure process. As disclosure can take up to weeks, months and even years, it is essential to develop relationships that establish confidence, trust and self-assurance.

As far as possible, disclosure needs to be carried out in a structured, planned manner. Creating an environment where the child/young person feels comfortable and safe is paramount. The maturity and age of the child must be taken into account and appropriate language used, and the child needs to feel free to ask questions, in conjunction with an open and honest approach. This point was highlighted by many teenagers, who felt that having a professional present in the disclosure would help, as their parent may be too upset to answer all their questions.

All the teenagers in the workshop felt that support after disclosure was vital. Many had been left feeling lost and afraid. TEEN SPIRIT provides a space where the young people can ask questions freely in a safe and supportive environment. Providing a chance for children and young people to meet with others in a similar situation was considered as one of the most important things to happen after the 'naming event'.

"For a child to be told about their HIV+ status, it gives them a chance to learn how to cope with this virus, to increase their understanding, and gives them a chance to ask questions. As they grow older, they will have the correct knowledge about HIV. Although some children and young people might not show an interest, at least they would have been given the chance to start their journey when they are ready and know why they are taking treatment, going to hospital and being sick." Sara aged 17 years

Talking to Young Gay People about Illness and HIV

Clint Walters

3.0 Health Initiatives for Youth: UK

Health Initiatives for Youth aims to support young gay and lesbian people living with HIV/AIDS; provide educational workshops in schools and prisons; promote the rights of young people in relation to policy issues; and raise community awareness. Health Initiatives for Youth has provided educational workshops to over 5,000 young people on HIV and sexually transmitted infections (STI) and collated data on the level of knowledge before and after the workshops. Over 79% couldn't identify the basic biological impact of HIV/STI. 88% also felt they wouldn't be able to disclose their HIV positive diagnosis to their family or many friends.

3.1 Issues for Sexually Infected Young People

Young people sexually infected with HIV/AIDS face a number of emotional and complex questions in learning to live with the virus. Dealing with life after diagnosis and figuring their 'own' way is crucial to maintaining a healthy lifestyle.

Many of the young people express concern about whether and when to disclose their HIV diagnosis to family, friends, teachers, work colleagues and potential sexual and romantic partners. Many choose to live in isolation with very close friends or family not even knowing. On many occasions they have told me that I am the first young person they have spoken to who they have felt able to disclose to and who is also young and has a HIV positive diagnosis.

Peer support is vital in breaking down the barriers of isolation. At present there is little specific advice, support, counselling and help with testing for this group.

3.2 Young and Gay: A Personal Perspective

"In 1997, at the age of seventeen, I contracted HIV. I had no counselling or preparation for what the test was, or the implications that it would have for the rest of my life. I was viewed by the doctors in Oxford as "at low risk" due to my age. However, after months of hospitalisation and countless days off school, while rapidly losing weight, they decided to test me for HIV.

I was told not to worry about the test, it was just a precaution. Seven days later I got a phone call from the specialist, a month before my 18th birthday, and they told me the results were "inconclusive and would I come in for some more tests." and "...not to worry." My mum took me to hospital and we went into the doctors' room. I rolled up my arm sleeve ready for the needle and my mum was beside me watching. It was then that we were both told: "I'm sorry. You are HIV positive."

I knew I had to be honest with myself and confront the fact that many people may reject me purely because of my HIV positive status. I was worried my own father may never speak to me again if he knew I was a carrier of the virus. I felt I had let my parents and myself down. The virus made me question the very core of who I was as a person. I was lucky enough to receive support at agencies across California – where I met young people living and working within the HIV sector.”

3.3 “This is what we think”

Clinics need to be accessible to young people both for testing and for follow up care where it is needed.

Developing a buddy system can be helpful. It enables young people to access support from someone they can relate to and can normalise their experience

“Young people feel that as far as treatment is concerned they don’t always have their views and opinions taken into account.” Young woman living with HIV

Sex education policies differ from school to school, creating a hit or miss approach to sex education. Young people’s involvement through committees within schools could help by providing greater awareness of the issues young people face and input around how best to meet their support and sex education needs. In the present system the quality of sex education differs between education establishments. As stressed by the Health Select Committee in their report on Sexual Health:

“... education [in schools] on relationships and sex [needs to be] given a high priority since the short and long term consequences of poor sexual health for young people... can be so serious”¹

3.4 Concluding Comments

There is a need for service provision aimed at young lesbian, gay, bisexual and trans-sexual people who are living with HIV. This needs to include greater access to sexual health education; there is an important role for health promotion, schools, youth education services and sexual health services in ensuring that young people have access to information. Access to appropriate peer support networks for these groups is essential in ensuring that their needs are met. The benefits of clear, accessible information and peer education are highlighted, by young people, in the report, by the Health Select Committee on Sexual Health¹.

3.5 References

1. House of Commons Health Committee Report on Sexual Health, (Paragraph 40, P.106). 11 June 2003, by Authority of the House of Commons. London: The Stationary Office Ltd

4.0 The Children and Young People HIV Network, National Children's Bureau

The Children and Young People HIV Network works to be an effective voice for children and young people living with and affected by HIV in the UK. It brings together national and community-based organisations, statutory agencies and young people themselves to inform and ensure child-centred policy and practice development. The Network is at present funded by the Department of Health and is based at the National Children's Bureau in London.

4.1 Disclosure Issues

"They know I'm sick but I didn't say it to them. I think they are trying to find out because they see the medicine – they read between the lines, but they didn't ask me for what. When I was in hospital they were panicking. I didn't want to tell them because if I told them, they might think I might have died. But they know I'm sick. But when they were [at the hospital] they found a letter about HIV and AIDS. And I told them "Yes, here there are HIV people". And they said "Is that what you have Mummy – HIV?" And I told them "No." If they knew they would be very worried. They would think I would die." HIV positive mother¹

4.2 Promoting the Voice of Affected Children and Young People

Providing adequate support around the process of disclosure is arguably one of the biggest challenges faced by service providers when trying to meet the needs of children, young people and families living with HIV. The discussions that arise highlight the conflict that sometimes emerges between promoting both children's rights as well as the rights of the parents. There are major implications in terms of meeting the needs of affected children and their families. It is generally felt that it is not the child's 'right' to know their parent's HIV diagnosis, as the 'right' to tell lies firmly with those infected with the virus.

The UN Convention on the Rights of the Child states that the child's best interests should be of paramount consideration (Article 3)². Therefore, consideration needs to be given to what is in the child's 'best interest', and we need to listen and learn from those children who have experienced this first hand.

This section offers the experiences of young people who talked frankly about either being told or finding out about their parent's HIV diagnosis and their views on the topic of disclosure in the context of being an affected child. The issue of disclosure of HIV diagnosis in relation to a sibling did not arise, but it is important to remember that an affected child unaware of a sibling's diagnosis can feel concerned about hospital appointments, periods of hospitalisation, medication. Reaction may vary from feelings of exclusion, guilt, jealousy and fear.

For some of the issues that arise, there may be no immediate solutions as these are entwined with the larger issues of global stigma and discrimination against those living with HIV, but we do need to acknowledge that these global attitudes will not change without open and honest discussion, which include the home and the family.

4.3 A Parent's Perspective

"I have faced this dilemma for many years, knowing that one day I will need to tell my children of my illness but at the same time I want to protect them for as long as possible. I have been positive over 12 years and have not disclosed to them, although there have been times when I have wanted to so much.

I still feel they need protecting from society, as it is evident that there is so much stigma attached to being HIV positive. It has always been, "When will be the right time? How will I do it? What is the right thing to say?" I know these questions are faced by many parents who want to disclose but don't know when.

I don't think it's possible to say that when a child approaches a certain age they are ready to be told. It's not that simple. Each child and their upbringing are completely different. For example, my two children would react very differently, my 12-year-old, I feel, would be able to cope with me disclosing to him and would understand the need to keep it a secret, but I don't think my nine-year-old would cope, or understand fully of what I was trying to tell him. I know that I owe them respect, that they need to be told, but I do believe there will be the right time and only I will be able to decide when that time is right. I don't want to put my children under any undue stress or pressure. Life is stressful enough without them worrying about me. I want them to have a 'normal' childhood like other children; there is no need at the moment for this to be 'spoilt'.

They know what they need to know at the moment. However, if they were to ever ask me, I would be open and honest, and answer their questions. But I have been lucky and they are both two accepting children, living their lives, not mine."

4.4 Affected Young People's Perspectives: "This is how it is for us"

It is generally agreed that if a parent has an illness, whether chronic or terminal, it is in the child's best interest to be given information about this. The manner in which and nature of information given, should depend on the child's age and understanding³. A child's involvement in a parent's illness can mean that the child does not feel/feels less isolated, confused or scared and that the child is able to ask questions, get correct information, and where necessary prepare for the loss of that parent.

"Children who are involved and informed when a loved one is terminally ill are able to start to work through the grief process in advance. . . In sudden loss there is no time for preparation or explanation."⁴

The stigma and discrimination of being infected with HIV complicates this. Many parents choose not to disclose their HIV status to their children, either not mentioning it at all, or referring to it by another name.

A focus group was held at the Karibu Project in Tooting, South London, on June 2004, to give affected young people a forum to discuss their experiences and views on parents telling their children about HIV in the family.

4.4.1 "Finding out"

The group spoke of how they found out about their parent's HIV status and ways in which they processed and dealt with the information. Experiences/themes included finding out 'by accident', 'not knowing how to broach the subject' and 'finding ways to cope with it'.

"I found out at nine years old by accident, from what someone said. I took it as playing 'Doctors and Nurses!'"

This particular young person overheard a conversation and then, as a nine-year-old, coped with the information by incorporating it into play, but did not speak to her parent about what she knew.

"Better to find out through parents than through sneaking around."

Another participant found a letter for their father that spoke about his HIV. They spoke to no one about this and waited for over two months before eventually confronting their father with the information.

Participants explained that the fear they felt was due to not understanding what having HIV meant. But they were pleased that they knew and although there were times when they worried or felt sad, their knowledge meant they could focus on enjoying and caring for their parent(s).

"If a child doesn't know and finds out after the parent has died, they will be left with the feeling of 'If I'd have known, maybe I could have done something, just to make their life better.'"

The group agreed that parents should prepare and tell the child as finding out 'by accident' was far from ideal and could lead to unnecessary and avoidable anxiety.

4.4.2 "Trust us"

Parents have stated many reasons for non-disclosure of their HIV status, these include fear that children will 'break the silence'; they will not be able to differentiate who it is OK to tell; age and development; telling would involve discussing embarrassing/awkward subjects; not being sick and therefore not needing to tell; they may find a cure; parents have not come to terms with living with HIV themselves.

When presented with these reasons, the group acknowledged why confidentiality is necessary in the current climate of discrimination and felt that people were afraid of HIV due to lack of information/knowledge.

"People don't really know about it – all people know are bad things. They think people will die – they don't see the positive things that/like people can live with it."

But they felt that this secrecy was about society/community and should not include them. They felt that parents underestimate their children and the level of understanding and empathy they have towards their parents and their situation. There was much talk about honesty and openness, and how children would feel having had such a major secret kept from them.

"Children feel things and may already know – parents should tell their children and not have secrets."

The issue they felt most strongly about was that of trust. When asked if they had ever discussed their parent's(s') HIV and regretted it, they all said they never even considered discussing it with anyone outside of those in their family who they knew were aware of the situation.

"If you tell me and trust me, I can recognise this. I'm not stupid, I'm not going to go out there and shout 'My Dad's HIV positive, or my Mum! It's not like we've just won the lottery. It's stupid to think that I would."

4.4.3 "How and when to tell us"

The group explored when and how to tell children and young people. They discussed what age they felt was the right time, and the manner in which the subject should be approached. The consensus was that the most important aspect of disclosure was first equipping the child with information about the HIV virus, transmission, the impact on health and the stigma people face.

"Educate them about HIV first, what it is, what happens, how you get it. Give them the knowledge and then talk about yourself once they understand."

The group was asked at what age they thought parents should start preparing to tell their child. After some discussion they agreed that this did depend on the child, the environment and their experiences:

"In Africa there is more death and disease, so children are used to seeing it and living with it, but here they are not."

But this disclosure should not be left too late (it varied between the ages of nine to twelve years old) and should really be a gradual process that happens over time and is directed by the parent.

4.4.4 "How we feel"

As stated earlier, parents often worry about the impact the knowledge of their HIV status will have on their children. They fear that by telling a child, they will cease to have a 'normal' childhood. The group shared their initial reactions and how they felt now about their parent(s) having HIV:

"It hurts at first, so painful, and every time she gets ill, that pain comes back."

Initial anger and confusion were discussed, but also how being included and involved helps you to get everything into perspective and appreciate what you have:

"Anyone would be angry and it takes time, but [you] need to stand by [your] Dad . . . be strong, have fun now, you don't know when he'll go."

They spoke about the living as an affected person:

"I have two people in my life with HIV. It hurts, but I am always there for [them] and [they] get all my support."

All felt at times sad and worried, but that given the option of knowing or not knowing, they would want to be told. They felt there is a difference between worrying because you are confused, scared and not sure what is happening to your parent(s), and worrying but being involved with and understanding what is going on.

4.5 Concluding Comments

To conclude, families are made up of a number of individuals and for each the experiences and interactions will be different, but children's views and their needs must be acknowledged.

The decision of parents to either tell or not tell not only impacts on their own and their family's lives, but also on the services supporting that family. Where children and young people are accompanying parents to services where knowledge is mixed, the enforced secrecy from society due to stigma and discrimination enters the very places where it should be safe to talk openly and share experiences. But the reason for this must not be forgotten. Parents who do not talk to their children about their HIV status make that decision on the grounds of wanting to nurture and protect their child(ren) and they themselves may not have come to terms with receiving a positive diagnosis. Parents need support through this process and perhaps need to be made aware of the positive impact that involving their children could have.

What the focus group participants made clear was that children need to be involved and that that involvement, after the period of initial shock, was the healthiest option for both child and family.

Finally, if we are to encourage disclosure, the support needs of affected children need to then be met. Community, statutory and voluntary organisations need to move towards providing children with services that they can access to have a safe space to share experiences and know they are not alone in what they face.

It is paramount that young people are involved in developing these services and informing the development of good practice in relation to professionals working with them.

4.6 Involving Positive and Affected Children in Policy and Practice Development

4.6.1 Principles of Good Practice

Children and young people are entitled to participate. This right, formalised in the UN Convention on the Rights of the Child (1989), entitles children and young people to express an opinion and have their views given due weight in all matters concerning them (Article 12).

The Children's Act (1989) reiterates this, in that it states that local authorities must consider the child's wishes and feelings.

Policy aside, to develop good practice and ensure that you are providing services that have the child at the centre and meet that child's needs at all ages, children need to be actively involved in the development process, from national policy development to service provision and local practice development.

In relation to living with HIV, children have specific needs that differ from adults. HIV can impact on physical and emotional development; building and sustaining peer relationships that are so essential during childhood and adolescence, feeling isolated from family and friends.

4.6.2 Health Care

Children's rights to health are set out in the UN Convention on the Rights of the Child (article 24), which provides the right to enjoyment of the highest attainable standard of health and to treatment and rehabilitation facilities. The inclusion of services users, which includes children, in service development, was structured in British law through the Health and Social Care Act 2001, section 11: public involvement and consultation.

Children and young people need to be involved in the development of both paediatric and transitional services. Their ownership and involvement in both their own health care and in the development of service provision is essential to secure ownership and provide services that meet their needs.

*"Some young people feel they can't ask questions [about their medication] and even if they did the language used by professionals can either be too basic and patronising or so technical that you have no hope of understanding what is being said . . . Young people often feel disempowered when talking to clinical or medical professionals."*⁵

It is important not to forget those young people who are accessing healthcare and support through adult services, either because there are no paediatric HIV services in their area, or that they were infected as an adolescent and immediately placed in adult services.

4.6.3 Support Services

For the majority of young people living with and affected by HIV, there are no specialist support services available. Many young people want to talk about the issues they and their family face, and also want to be in a 'safe' environment and interact with other young people facing similar issues.

"I enjoyed being here today, talking about HIV for me is really emotional because my Dad has got it. Being here in this group gives me an opportunity to talk about my views and listen to other people's views about HIV."

When developing services for children and young people, their involvement needs to be from the outset. Consultation on format, structure and regularity of services, as well as naming a service, will lead to ownership, commitment and ensure these services cater for and are used by those who need them.

4.7 References

1. Elizabeth Lewis, (2000), *Afraid To Say: The needs and views of young people living with HIV/AIDS*, London: National Children's Bureau
2. United Nations (1989) *The Convention on the Rights of the Child*. Adopted by the General Assembly of the United Nations on 20 November 1989. Geneva: Defence for Children International and the United Nations Children's Fund
3. For further resources on age appropriate methods, visit www.cwac.org/publications
4. Lask, B, Taylors, S and Nunn, K, (2003), *Practical Child Psychiatry: The Clinician's Guide*, London: BMJ Publishing
5. Report on UK seminar held in June 2004. *Children's Rights and HIV: Practice issues for those working with children and young people living with and affected by HIV*. Report available through www.ncb.org.uk/hiv

Appendices

Useful Contacts

Useful Contacts in the NHS

St Mary's Hospital

Paediatric/Family Clinic and HIV Team
Clinical Psychologist, Diane Melvin
Tel: 020 7886 6816

Great Ormond Street Hospital

Paediatric/Family Clinic and HIV Team
Clinical Psychologist, Alex Divac
Tel: 020 7829 8896

Newham General Hospital

The Sun Clinic
Family Focused Clinic and HIV Team
Clinical Psychologist, Rekha Vara
Tel: 020 7445 7777

St George's Hospital

Paediatric/Family Clinic and HIV Team
Clinical Psychologist, Sarah Waugh
Tel: 020 8770 8181

Children's HIV Association of the UK and Ireland (CHIVA)

This Association has been founded as a sub-section of the British HIV Association (BHIVA) for all professionals involved in issues relevant to children infected or affected by HIV.
www.bhiva.org/chiva/index.html

TEAM Youth clinic at the Mortimer Market Sexual Health Centre

Contact Senior Health Advisor: Mike Jones.
Tel: 0207 530 5050

Useful Contacts in the Voluntary Sector

The Children and Young People HIV Network

Direct line: 020 7843 1911
www.ncb.org.uk
Email: mconway@ncb.org.uk
Join the Network to receive updates of its

work, news and events. Send a blank email to: join-hiv-news@ncb-lists.org.uk

BODY & SOUL

A UK charity supporting children, teenagers, women, heterosexual men and their families who are living with or closely affected by HIV and AIDS.
www.bodyandsoul.demon.co.uk

Children with AIDS Charity (CWAC)

Children With Aids Charity was set up to help the youngest of those affected or infected by HIV and AIDS. It is a national UK charity with the simple aim of working towards a future without prejudice for these children and their families.
www.cwac.org

Positively Women

www.positivelywomen.org.uk

UK Coalition

www.ukcoalition.org

Health Initiatives For Youth: UK (HIFY-UK)

HIFY-UK's mission is to provide emotional and practical support to HIV positive youth and to empower all young people with accurate, age-appropriate information about HIV/STI's to ensure that they make the best possible decisions regarding their sexual health and personal well-being.
www.hify.org.uk

UK Gay Men's Health Network

www.gaymenshealthnetwork.org.uk

General Useful Contacts

Avert Statistics and downloadable resources

www.avert.org

Terrance Higgins Trust

www.tht.org.uk

National AIDS Trust

www.nat.org.uk

GENERAL USEFUL CONTACTS, CONT'D

The Elton John AIDS Foundation

www.ejaf.org

Crusaid

www.crusaid.org.uk

African HIV Policy Network

www.ahpn.org

Useful Resources

Talking with children about illness and HIV

Produced by Children with AIDS Charity,

www.cwac.org

Talking to children with HIV about

their illness

Produced by the St George's Paediatric

HIV Team. Available on the CHIVA website:

www.bhiva.org/chiva/index.html

Guidance on explanations about HIV

to children with the infection

Produced by Clinical Psychologist,

Diane Melvin, for the St Mary's Paediatric

HIV Team. Tel: 020 7886 6816

Older children with HIV: Informing them

about their diagnosis

Produced by Clinical Psychologist,

Diane Melvin, for the St Mary's Paediatric

HIV Team. Tel: 020 7886 6816



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