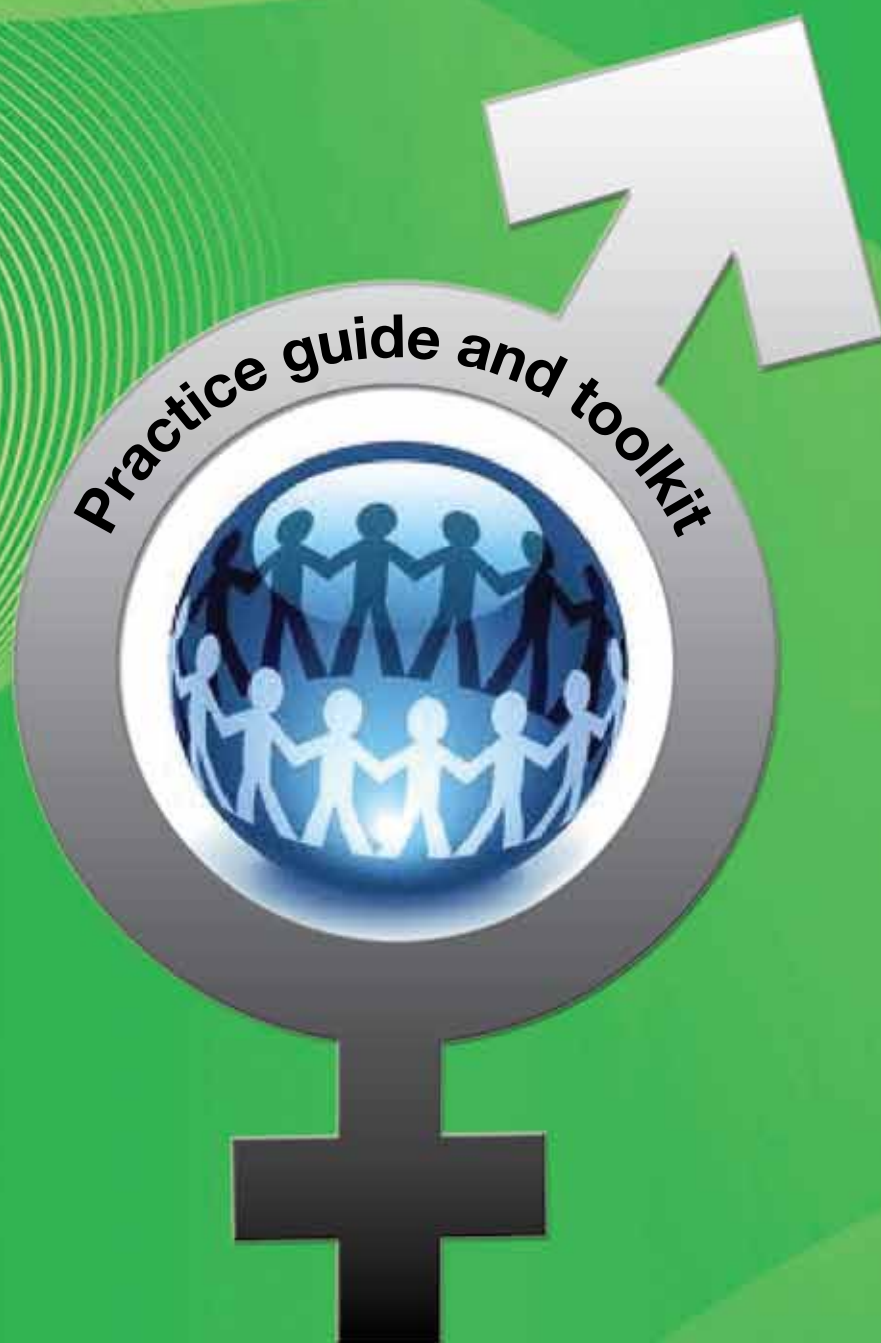


It's **Good2talk**



**Supporting children and families
in talking about HIV**

The UK Family Project

In 2008, Babs Evans, Grant Manager for the Elton John AIDS Foundation brought together UK based organisations to look at the needs of children and young people with HIV. We discussed how we could work collaboratively to support these needs. Two of the main challenges were, how stigma and discrimination ensures that HIV is treated as a secret in families, effecting communication on HIV, sex and relationships for children and young people, and how organisations, spread across the UK, could improve our work together, share good practice and feel part of something bigger.

The UK Family Project then formed; a partnership between Positive Parenting and Children (London), Waverley Care (Scotland) and the Regional HIV Social Work Team (Northern Ireland) of Belfast Health and Social Care Trust, funded by a generous grant from the Elton John AIDS Foundation

The UK Family Project is a collaborative initiative that aims to reduce the impact of secrecy and stigma on families living with HIV, facilitate more comprehensive and earlier testing for undiagnosed children, improve family communication on HIV, sex and relationships and ensure that families receive support using the best possible practice models and methods.

We achieved our aims through a number of UK wide activities and developments

- organised two family residentials (October 2009 and October 2011)
- co-ordinated a practice sharing and networking event for practitioners who support families living with HIV, in partnership with CHIVA
- established a network of support and social care professionals / practitioners
- developed a guide to models and methods of support for families living with HIV
- agreed planning and development that supports the testing of children and young people at risk of HIV
- service development in Northern Ireland
- developed a series of resources for communication and talking about HIV within families called 'It's Good2Talk'. Underpinned by research and evidence based good practice, it has been shaped and informed by parents, young people and practitioners across the UK.

'It's Good2talk' will help

- practitioners in their support for children, young people and parents in the challenges HIV places on communication
- individuals and families to feel supported and better able to talk openly about HIV within the family, and
- parents, who have children of all ages, be able to have more open and age appropriate discussions on HIV, sex and relationships.

Acknowledgements

We are particularly grateful to EJAF for funding the UK Family Project, encouraging collaborative working and for allowing it to happen. The collaboration has not been just between organisations but with children, young people and parents who have taught us so much. We would particularly like to acknowledge them and the way they have talked openly about their personal situation and encouraged us along the way.

This document was written and compiled by Victoria Morris, UK Family Project Co-ordinator, Positive Parenting and Children. A big thank you to the project partners, Claire Dallas, Pat Knowles, Jeremy Sandell and Lynne Williamson, and colleagues at PPC in particular Florence Abalo, Richard Backes, Rebecca Brown and Nina Bengtsson and for all their advice and patience.

Special thanks to the UK Family Project Advisory Group, South London Sharing and Telling Network, Parents and young people who attended the October 2009 and 2011 residential weekends, Amanda Ely (Chiva), Jill Hellings (Barnardos), Emily Hamblin (NCB) and the paediatric HIV team in Karolinska Hospital, Stockholm.

Some Parents are fearful for their children and themselves if they are open about HIV. We respect this but at the same time we see the preschool child, with a mother who is depressed and isolated, desperate to leave the house for the support session, the school age child who is worried because her mother is too tired from adjusting to her new medication to get up in the morning, the young person whose parents can't face their own diagnosis let alone work with the hospital to tell their child about theirs, the young carer who understand he needs to help out because of the HIV, but can't find out how Dad is because he doesn't know how to ask and his father doesn't talk about it. We knew we had to find a way to be clearer how we worked with families in relation to this knowledge issue and 'disclosure' and we realised we weren't the only ones when;

- we formed the South London Disclosure (now Sharing and Telling) Network
- it was identified as one of the main barriers for parents who children need to be tested for HIV
- we became a partnership and formed the UK Family Project
- we held the Practice Sharing Day and met other professionals and organisations who said it was one of their main challenges in their service delivery
- it became the first focus in CHIVA's development of standards for Social Care

With a future in mind where a family living with HIV can be open in the home about it, **'It's Good2talk'** enables us to walk side by side with them on their journey.

Victoria Morris
UK Family Project Co-ordinator
Positive Parenting and Children

Contents

The UK Family Project	1
Acknowledgements	2
Introduction	4
From ‘disclosure’ to ‘sharing and telling’	5
A person’s HIV status is confidential because	5
Disclosure of HIV is complex because	5
The impact of stigma	6
Stigma in the African community	7
Why share and tell	7
How to support children and parents to share their HIV status	9
The journey	10
Readiness	11
Parenting styles	12
Afterwards	13
Selective/targeted approach	14
Pathways and a multidisciplinary approach	15
Opportunities for families to access support for ‘sharing and telling’	16
Resources	18
Further resources and websites	20
References	21

1.Introduction

This guide and toolkit is designed for professionals and practitioners who provide support for families with HIV across health and social care. This document puts a focus on disclosure, why it's a difficult issue and is one of the main challenges of support work with families with HIV. The aim is to provide a practical approach drawing on research and theory.

Disclosure in this context, is the act of telling someone that you have HIV or that you are affected by HIV. Disclosure implies that this information by definition is a secret or is confidential. Disclosure is a longstanding complex issue, not least because there is actual and anticipated experience of stigma and discrimination with a disclosed HIV diagnosis. Stigma can involve being gossiped about, verbally or physically harassed or threatened, and verbally insulted or physically assaulted¹. Actual stigma and anticipated stigma constitutes a barrier to disclosure to others, in particular schools and community members. The research of the UK Family Project with parents and young people confirms this².

For child with HIV there is a momentum towards disclosure from the day of diagnosis, so that they can know their own diagnosis and be at the centre of managing their condition. The current CHIVA (Children's HIV Association) guidelines and standards on talking to a child or young person about their health and diagnosis are available on their website³. Disclosure of a parent's status to their affected child does not have the same clear ethical grounds as disclosure to a child with HIV. It is generally accepted that more thought and planning goes into the telling for children with HIV than those affected. Parents can be reluctant to communicate to their child that they have HIV because of stigma and discrimination. Describing disclosure in these terms gives an impression of a decision made to do so, a planned event. However, disclosure can be abrupt, unplanned, and accidental. The need to avoid this more devastating method provides one of the main drivers to planning disclosure for those who are affected by HIV.

For parents with HIV, telling their children is a primary concern: how, when and what to say. In the UK the majority of families living with HIV are African; there is the fear and experience of the double stigma of immigration and having HIV, as well as dealing with shifts and changes to social and familial support of moving country. In Scotland, the connection of HIV with drug misuse is a significant factor (pviii Cree et al)⁴

¹ The People Living with HIV Stigma Index (2009)

² Kinouani et al (2011)

³ <http://www.chiva.org.uk/health/guidelines/talking>

⁴ pviii Cree et al (2009)

2. From 'disclosure' to 'sharing and telling'

Disclosure implies that there is a point of not knowing and then knowing, a revealing; that this information is by definition as secret or confidential.

A person's HIV status is confidential because

- it is a personal health issue/medical information, so any kind of diagnosis can be understood to be a personal matter with a process that will take a person from their own adjustment to the information to the position where they may be open about it.
- The diagnosis is a significant one, there is no cure and within this lifetime people have died, and continue to die in parts of the world where the provision medication and health care are affected. This is very relevant to those with links to those countries as the association with death will affect decision making in relation to disclosure.
- There is an actual and anticipated experience of stigma and discrimination reported by people who have made others aware of their HIV diagnosis

Disclosure of HIV is complex because

- it is a sexually transmitted disease for the majority of cases and in the minds of the general public. People are incredibly curious about transmission and how it occurred
- the public remain generally uneducated about HIV
- there are a range of reactions to HIV; from tolerance, sympathy, indifference to violence, rejection, disgust. People prepare for an adverse reaction when they wish to share their situation.
- there are legal implications relating to the transmission of HIV.
- despite diagnosis some live in denial. There are ways that this may also be encouraged i.e. an expectation that they will be healed through prayer.
- passing on HIV through an intimate sexual act or by giving birth/breastfeeding can be a huge emotional burden.
- a young person with HIV may be conscious that by sharing their diagnosis, they are sharing their mother's diagnosis if acquired vertically. Mostly HIV is relational, if transmitted mother to child or through sex. By sharing your HIV status you may well be indicating that someone else has HIV.
- people are devastated by an HIV diagnosis and it is an enormous task to come to terms with it. Many people are arrested by feelings of shame and guilt, and fear rejection if they tell someone they care about.
- when telling others, skills are required to be prepared to deal with the consequences, be in a position to support them, to manage awkward questions, have conversations that may quickly be about sexual behaviour not normally had. Personal issues may not normally be discussed with those who have been shared with; there may be trust issues/ fear a violent or cruel reaction.

- there is a worry about burdening others, and how information will be kept private
- of concern about what it may do to intimate sexual relationships, and family/friend relationships – being seen as victim, someone in need of care etc.
- accurate information about HIV and sexual health will need to be provided, an explanation on keeping it private and awareness of stigma.
- of fears of indiscriminate onwards disclosure (losing control of who knows) i.e. a child tells his class mates or it's passed onto to family members who would not have been selected to know.

All these factors demonstrate the challenges and barriers faced to people with HIV who would otherwise want to share their diagnosis and feel the support of those around them, they also demonstrate why the concept of 'disclosure' has been useful. In this practice guide the reader is encouraged to move away from the use of the concept of 'disclosure' to less stigmatising ideas of sharing and telling, awareness, that enable more openness in family life and organisational approach whilst maintaining confidentiality.

3. The impact of stigma

'You can't expect parents to disclose to their kids when there is still the stigma around HIV' young woman, affected by HIV (2011)

Stigma is the main barrier for telling anyone about HIV. In our residential research we found that

'reports of the improved closeness and trust in a family or parent child relationship on the one hand, and the discrimination and stigma experienced as a result of disclosure of the other, illustrates the contrasting considerations that parents have to balance in their decision-making about disclosure'.⁴

Stigma and community attitudes surrounding HIV can prove to be a greater source of stress than the actual illness.⁵ Alongside this, is the issue of internalized stigma where

'consciously or not, some people with HIV think that their identity and worth have been damaged or spoiled because they have HIV' ⁶.

Experience of stigma in the African community is perceived as being more acute – see text box below.

⁴p9 Kinouani et al, 2011

⁵p. 354 DeMatteo2002

⁶p12 NAM 2008

⁷Taken from slides from the presentation 'HIV-stigma: What is the impact for HIV+ adolescents? Evidence, issues and challenges' by Dr Tomás Campbell, Clinical Psychologist, Newham. 27/6/11 **Sex, STIs and stigma: Challenges for HIV-positive adolescents in the UK and Africa** Royal School of Medicine

Stigma in the African community

- HIV-stigma is a big issue for African people (Prost, 2008)
- What is the evidence? Late HIV diagnosis, low perception of personal risk, variable knowledge of HIV transmission routes, difficulties with status disclosure to new partners
- Condom use – associated with lack of fidelity, gender inequality re; use
- Immigration issues can affect relationships with health care providers
- Many Africans have already had experience of HIV in their own families and communities
- They may have witnessed highly stigmatised attitudes and behaviours
- More difficult to cope with their own status within this context
- Poverty and unemployment affect social isolation and health outcomes

Stigma and young people in the UK

- There is little literature on the impact of HIV-related stigma and young people
- The context in which young HIV+ people are developing and maturing is one in which HIV-stigma is a reality
- HIV-stigma may be highest in the very communities from which most young HIV+ people themselves come

Dr Tomás Campbell 27/6/11 ⁷

4. Why share and tell?

In the face of stigma and the legitimate concern about how a child will handle it, why would a parent tell their child? If their child has HIV they will be working side by side with the child's paediatric team to give them information about the virus leading to a naming day. But for that child, and their siblings, as with other children of adults with HIV, the sharing of the parent's diagnosis may be a separate process or event⁸.

After they have told parents may feel relief and report more closeness,⁹ but most children report feeling sad or upset having known about HIV (84% in DeMatteo study 2002). Adjustment is harder with age, though can be short lived for some. Hawk¹⁰ identifies that children will worry more if the mother is ill at the time, and it's best to tell them earlier, before this. There are gaps in research on the effects on children and young people of knowing their parents' HIV diagnosis.

⁸ Prost (2008)

⁸ Miah et al (2004) recognised that this may need to be a separate conversation for parents of children with HIV, and peer support opportunities should be explored p11

⁹ 'Many mothers do perceive better relations with children following disclosure, citing more closeness, expressed affection, and children's supportive behaviours' (p666, Hawk)

¹⁰ p666

Parents living with HIV do not have to share their diagnosis with their affected children, however, it is useful for all parents to plan how to share their diagnosis and be aware from when they have young children what they need to think through so they can make informed choice about this matter. HIV is a long term illness and there is a high likelihood that their child will find out at some point, even as adults.

“9 out of 10 women did not regret telling their child”, though some had not planned for the event and just blurted it out.¹¹

These are some of things parents have said¹²

- I can reassure them that there is health and life after diagnosis, especially with medication. It's not the end of the world.
- They will find out accidentally or they will hear of it from someone else, they will get angry, blame me and lose trust
- I may tell them in a bad way during an argument.
- I have raised them to be honest and truthful
- They will feel trusted
- I think they know anyway, I will tell them so they need not worry
- We will be closer as a family
- The child will be able to help if something happens and know what to do
- I won't need to hide my medication

Here are some of the things young people have said¹³

- It would have definitely made me feel more at ease if she had talked to me more because I was always so worried about her. To me sharing is essential.
- If I could advise any parent in my parent's situation, I would say please tell your children earlier, don't wait until they are mid teenagers or older
- I wouldn't have secrets like this from my children. It's better to know even when things are bad like a sickness.
- The knowledge and awareness had helped me to be stronger.

¹¹ Ostrom Delaney et al (2008)

¹² Taken from research, residential work, consultations and the advisory group, and collected together in 'It's Good2Talk' parent resource

¹³ Positive Parenting and Children (2011)

De Matteo et al ¹⁴ asked children and parents to rate reasons why the parents should tell children about HIV and the ones that came out top, particularly for children, were linked to trust – providing honest answers to children’s questions and to maintain family trust.

5. How to support children and families to share their HIV status

Some organisations, in close partnership with their colleagues in health, have developed a clear pathway of support for families in relation to talking to children and young people about HIV, especially those with HIV. For most of us working in the sector providing a clear approach and the right support for children, young people and parents is a practice challenge. At the time of writing, many of us are thinking about and discussing how a child’s rights to know their status and have HIV treated like any other illness may affect our approach and bring more honesty to our service provision. We are considering our use of the concept ‘Disclosure’. Challenging ourselves to consider whether such a concept is communicating that the telling of HIV is the revealing of a secret. Are we contributing to the stigma unnecessarily? What other illnesses do we talking about ‘disclosing’ the diagnosis? In practice we may use more neutral phrases such as ‘talking to children about HIV’, ‘sharing your HIV diagnosis’. Are we providing an honest and open environment within our services that does not reflect the secrecy and stigma experience of HIV? CHIVA are producing Quality Standards to enable organisations to achieve these aims.

Many of us struggle to know where to start with helping parents through disclosure. It’s a complex issue and we are trying to balance the needs of the child with the parent’s right to privacy, in the face of societal and community stigma of HIV.

Simply put, services need to provide assistance and guidance for parents as they decide; and to provide support services to help children cope.^{15 16} Good quality support and relationships are the main ingredients to success; resources are a tool but not sufficient on their own. Receiving support from professionals can reduce the need for people to seek their own social support; look to provide peer support and opportunities for parents to talk things through with others in the same situation.

Discussions in relation to talking to children about HIV can even be useful with parents with young children.

¹⁴ p.348 (2002)

¹⁵ p 879 Ostram Delaney (2007)

¹⁶ Parents need age-appropriate support about when, how and what to tell their children about their own HIV status, and about the disease generally. Parents need guidance on managing children’s responses, and on planning for the future. Additionally, in the development of support mechanisms to advise guardians on how to discuss HIV and sexual health in general with children, the changing family roles and typical intergenerational modes of communication need to be taken into consideration. This might contribute to providing vulnerable children (and orphans) with access to life skills to mitigate the impact of their vulnerability through identifying suitable support mechanisms for them in addressing these issues (p 393 Nam et al 2009)

The journey

Many parents consider how and when to tell but for young people it's how things are discussed after that can have the impact.

Whilst there is HIV stigma, sharing a diagnosis will be difficult. Support should focus on improving family communication, self-esteem and resilience, and helping individuals come to terms with their diagnosis. Listen to the parent, they may not have discussed this with anyone before - avoid being judgemental. Parents should be encouraged to use support to think it through, and be provided with opportunities to do so, with peers or professionals, or both. Parents and young people value the support they receive in this matter.¹⁷

'Parents need to be able to share experiences when making decisions about disclosure and other parenting concerns. Methods can include groups, workshops and courses, social events and outings, online networks, residentials and befriending and mentoring schemes. Support and intervention needs to respond to the different personal circumstances and hold in mind the number of factors in play when deciding to disclose.'¹⁸

There are tasks in the planning that we can support and facilitate, one of the most important ones being helping the family create a supportive environment for HIV to be talked about, when children are told and after.

Parents are likely to consider telling their child when they are diagnosed, but it is common to delay. For mothers this was mainly because they wanted the child to have a good childhood and for the father they felt their child wouldn't understand. HIV positive adults were most likely to delay because they didn't know what to say and they needed to tell someone first (but would say earlier if they fell ill or child started asking questions).

Help plan by using resources like those included here, if you are knowledgeable on child development this can help provide a structure for telling. It's a process, not one conversation; a child cannot take in such a complex subject all in one go.

¹⁷p.9 Kinouani et al, (2011)

¹⁸p.14 Kinouani et al, (2011)

Readiness

Sharing one's HIV diagnosis within the family is essentially an act of trust. Firstly, parents need to trust themselves that they have come to terms with their HIV diagnosis and feel ready to share. Then, trust needs to be present in the relationships before the parent feels ready to share. Parents will need to know that their child can keep a family matter private, and allow it to stay within the family, that the parent-child relationship is strong enough to cope and the child will not reject them but feel a closer bond and inclusion in family matters. They also need to know that they will be able to manage as a family unit and not least that the child and the family wouldn't experience discrimination from the community or society at large.

General support around family communication is well worth providing at this stage. It will help facilitate at the time of telling the child about HIV, and more importantly to keep the conversation going afterwards. The **'It's good2talk'** material provided by the UK Family Project is designed for this purpose.

Parents can be 'showing' (rather than 'telling') something important to their child, by being secretive in matters relating to their health, medication and hospital visits. Alternatively they maybe leaving around the house letters from the hospital openly take medication or take the children to support services and clinics without explaining why.

In conversations you have with parents in sharing their diagnosis it may be worth assessing to see if these behaviours happen. A parent who is not trying to hide their health matters may want their child to know but need support in having the conversation with them. Are they leaving clues around? Are they attempting to be open but can't cope with actually saying the words. Is it fair to a child to 'pick up' on the clues but not know for sure, not have the opportunity to ask questions and calm their fears?

These are ways in which children and young people may 'know' but not have the opportunity to voice it and therefore may worry and become anxious. Parents don't always know when their children are worried. Telling and sharing about the HIV can therefore come as a relief.

In DeMatteo et al study into the paths families take to 'truthtelling', they asked parents to rate things they did to prepare themselves:

- talking with someone they trusted (78%)
- deciding to tell while the infected person's health was good (71%)
- prayer (50%)
- talking with professionals (49%)
- women were significantly more likely than men to have included written materials (e.g. books, pamphlets) in their preparations¹⁹.

¹⁹p.344 DeMatteo et al 2011

Another aspect which is useful to consider in 'getting ready' is what DeMatteo calls parenting styles, which he divides into three types²⁰ - see box. Within a couple their maybe conflicting parenting styles affecting agreement about if and when to tell.

Parenting Styles

1. Viewing children in need of protection

Parental role: to keep information from the child that might cause worry and lose his childhood.

Most likely to keep the information private from the child

2. Viewing children as developing capabilities, with independence and autonomy encouraged and supported

Parental role: to decide and determine when was best for that child to know

Most likely to delay telling the child.

3. Viewing children as integral to family, a family is where all members draw strength and support, mutuality.

Parental role: to keep child included in what is happening, good and bad, and face the challenge of HIV together.

Most likely to be open about HIV

In relation to delay, many wait for the child to get older so they can handle the information and to cope²¹, however, young people in adolescence are more likely to have an adverse reaction than younger children. This may be because the information gives them more responsibility at the same time that they are striving for independence.²²

In practice, a model of openness has been demonstrated by families across cultures, involving aunts, uncles and cousins in the process – the genogram and ecomap can help facilitate this.²³

Parents often make the decision to share their diagnosis with their child based on maturity which can lead to the older child in the family being aware whilst a younger child might be unaware. Whilst there is no evidence that this is harmful (DeMatteo 2002), it will add complexity to information sharing within the family.²⁴ For many parents they will need support in feeling confident they have the right information and know what to say.

²⁰ p 344-5 DeMatteo et al 2002

²¹ p878 Ostram Delaney 2007

²² p 667 Hawk

²³ Guidance on using these tools is provided within 'It's good2talk – supporting communication in families living with HIV'

²⁴ p661 Hawk 2007

Afterwards

After the child or young person becomes aware of their parents diagnosis the parent often feels relief. The young person is likely to feel sad and will have a reaction. As practitioners we frequently share stories from young people, both with HIV and affected, that the point of telling is the only conversation they have with their parents about HIV. They are then left to deal with this issue on their own. For the young person there needs to be an extra effort by the parent to help them cope. Each young person will have their own coping strategies. Initially these may include listening to music, watching tv, crying, playing with a pet, sleeping or eating, seeking a friend for companionship or comfort, or seeking adult for companionship or comfort²⁵.

There is a lack of research with long term impact of becoming aware of HIV within the family for children and young people. In 'It's time to talk' four affected young people who tell their stories paint a picture of the need to talk things through after they became aware of their parents diagnosis and demonstrate the intensity of adjusting to this situation²⁶.

"Brackis-Cott et al. (2003) noted that youth felt more comfortable discussing the mother's HIV when she could provide information in a caring way, when youths could pretend they were discussing a third party, when the discussions were proactive, and while watching programs about drug use or sex. Mothers in this group found it helpful to begin HIV discussions in the context of their own treatment. Encouraging and responding to offspring's own questions can help mothers to discuss HIV in a developmentally appropriate way (Armistead et al., 2001)."²⁷

All young people should be able to benefit from meeting others in the same situation through a structured group, event or network. This will help normalise their situation and develop coping skills.²⁸

The child or young person may provide more emotional support after they have been told about their parent's diagnosis, and take on further caring responsibilities. Assessing them and supporting them as young carers should be considered. The Include Project at The Children's Society have produced resources to support the practitioner with this process (see resource section).

²⁵ P346 DeMatteo et al (2002)

²⁶ Positive Parenting and Children (2011)

²⁷ p 665 Hawk (2007)

²⁸ For further ideas see 'Practice and service delivery models' UK Family Project (2011)

In addition, family events that address communication, and provide emotional and parenting support post 'sharing', may help young people who are aware, but who may down play the impact and not take up opportunities for support – address communication, emotional and parenting issues.

Selective/targeted approach

It may be useful to help a family together or as individuals, think through who they or their child could talk to, and how to decide who could be trusted to handle the privacy of the information. Being able to do this, especially in relation to potential partners was a concern for parents in both the residential weekends we ran in 2009 and 2011.

Help finding 'safe people' for the child to talk to may fit the situation better at times where the parent child conversation is too difficult. Telling younger children who they may share the information with, may help with the stress and anxiety of keeping the information to themselves. A genogram or ecomap is useful identify the right person.

Consider:

How do they handle confidential matters?

How do they talk about other people?

Do they gossip or are they respectful about privacy?

If they were no longer close friends would they use this information to hurt?

Are they a good listener?

Are they supportive and reliable?

"You may feel like telling people soon after you receive your HIV diagnosis - but remember that once you've told someone you can't 'un-tell' them.

Here's the advice from the 'My HIV website'²⁹ about choosing who to tell –

Things to think about include:

Why do I want to disclose my HIV status to this person?

Are there any benefits to telling them?

Are they good at talking about emotional issues?

How would I like them to react ideally?

What will I do if they don't react in the way I expect or hope for?

Can I trust them not to tell other people?

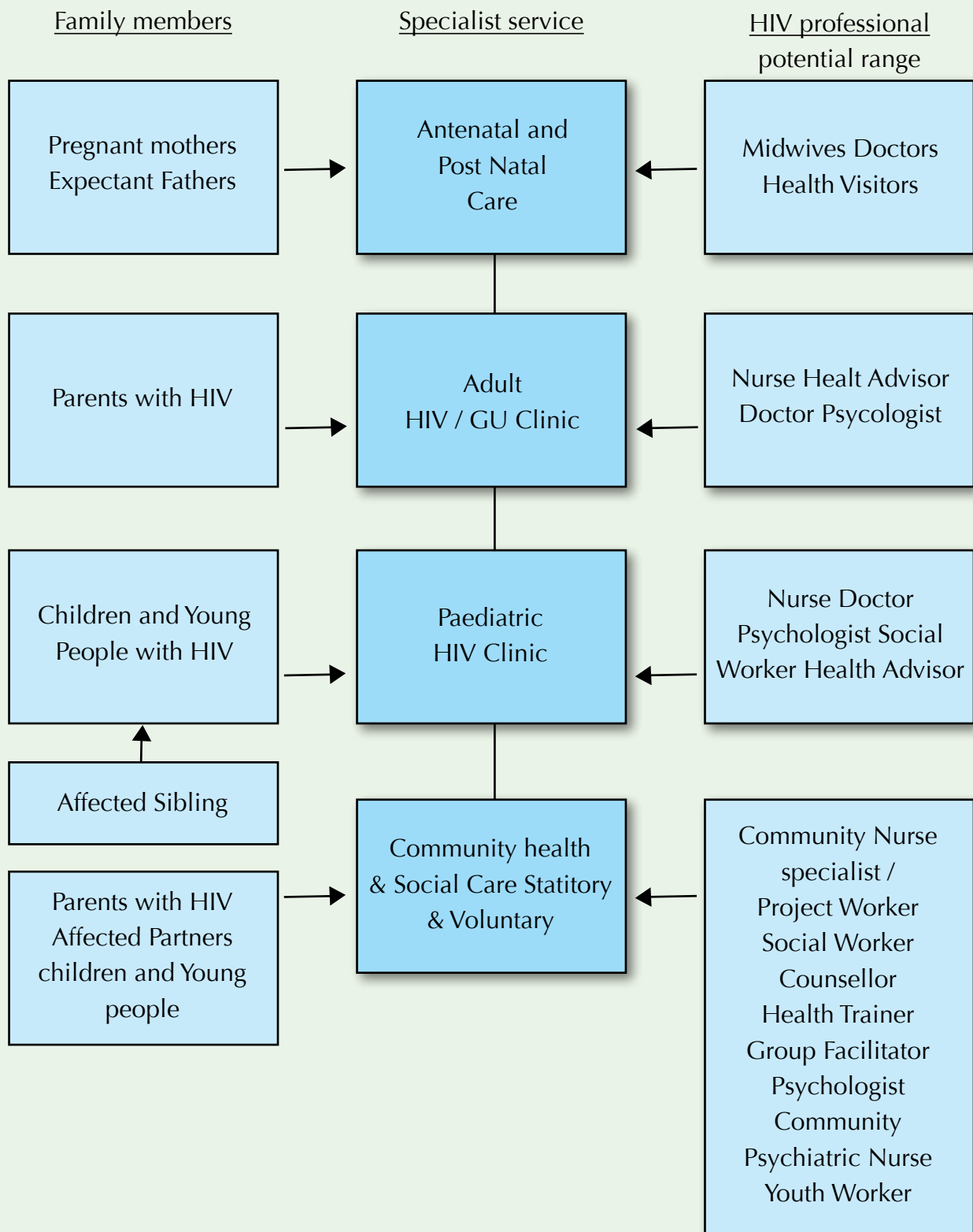
Telling someone that you have HIV can be a very positive experience and will hopefully mean that you have someone to offer you support."

The reaction of the other person is worth preparing for and to have accurate and up to date information to hand about HIV to share.

²⁹ The website is provided by THT and further information on telling people can be found at <http://www.myhiv.org.uk/Telling-people>

Pathways and a multi disciplinary approach

All parents should be offered an opportunity to 'talk things through' with an HIV specialist, the diagram below shows where this could be provided. For many parents, telling a partner or someone they would like a relationship with is also important and the process is similar.



There are many professionals that could potentially be involved in offering this opportunity, overlap may not be a problem but contrasting advice will be. Working together according to local multi-disciplinary protocols and practice is essential. Knowing what support (from family, friends, professionals and support organisations) there is for the child, young person and parent afterwards, is important before the beginning of the conversation.

For the majority of parents of affected children and young people, attending adult clinic appointments will be the main route to talk things through.

Children and young people with HIV will learn of their diagnosis with the support of the paediatric health team where they receive their care, in partnership with the parents.

Parents of children and young people with HIV

Sharing the parent's own HIV diagnosis with a child with HIV, and telling other children in the family of their sibling's diagnosis should also be discussed with the parent specifically and viewed as an additional task.

Parent's accessing adult services should be asked during the information taking / assessment stage if they have children (questions about whether the children are tested can also be asked at this stage) and details taken on age, where they live and who they live with³⁰.

Suggestions on what to say to parents –

Have you thought about telling your child about your diagnosis?

How much do you think they might know?

It can be helpful to talk it through and to plan what, how and when you might tell them, even if you don't feel ready.

They might find out by accident or by guessing or because you tell them in a way you might regret.

If you have planned then you will be able to give them a chance to talk it through with you and help them cope with knowing.

³⁰ Genograms can be useful for collecting information like this, and can be annotated and kept on the file for future reference. See The UK Family Project ... for further details of how this tool can be used in relation to communication and talking about HIV

Pregnant mothers are encouraged to tell their partners during pregnancy³¹, it is an opportunity for parents to discuss and plan to tell their children (particularly if they already have children), and in the post natal period, at the point of the final test result. If the child tests HIV negative, on discharge the parent could be given verbal information and written resources about telling their child, including how to prepare the ground by good communication and treating the illness like any other, involve them and bring them to appointments.

If a child tests positive then the same advice can be given, and that planning around telling will be achieved hand in hand with the child's paediatric team.

Affected children and young people may access HIV support services that their parents don't attend. These services will know through their assessment whether they are aware of HIV within the family and their level of knowledge. If the child or young person is not aware, then the service should consider how long they would offer HIV specialist support to the child/young person and how they could support the parent in telling their child. Where support services have no specific support or group for parents, occasionally gathering parents together to facilitate a discussion about this would be very helpful, even if the parents have already told their child. The support a child needs from their parent after knowing about HIV is just as significant as the support a parent needs to come to terms with HIV and think through telling others.

Where there is statutory involvement by Social Care within a family the opportunity to talk things through should also be provided. There are a huge range of reasons why a family is receiving a statutory intervention which may be complex, and time and resource constraints do not lend themselves to addressing this issue in full. Use a multi-disciplinary approach to resolve this.

³¹ P463 de Ruiter et al 2008

Resources

The UK Family Project has produced a series of five resources, including this guide, focused on communication and talking about HIV, called **'It's Good2talk'**. The resources can be used for families with children of all ages.

The **'It's Good2talk'** workshop, parent resource and practice guide and toolkit on communication are all aimed at supporting parents to develop the skills and confidence to talk about HIV, sex and relationships. They help parents provide family life with the platform to talk to their children about HIV, and will enable young people to hold conversations with their parents after they become aware.

If communication within the family is a barrier to talking about HIV, take some time to work on this. The **'It's Good2talk practice guide and toolkit on communication'** is specifically designed to address this issue and go with this guide on supporting families in talking about HIV. It has useful tools such as the genogram and ecomap, which help practitioners engage with families and prepare the ground for talking more openly about HIV, sex and relationships. Use the genogram and the ecomap to establish with the parent and the child and young person who might be a supportive trustworthy person, within or close to the family, to involve pre and post disclosure. Getting the environment ready but also proactively exploring the nature of the family relationship and any tasks that can be worked towards to improve it. For example, a genogram may highlight lack of communication in relation to HIV between a father and mother that will need some improvement before the event. The need for family-based, intergenerational HIV-treatment programmes has been recognized as an important consideration by Rotheram-Borus, Flannery, Rice, & Lester, 2005³².

The **'It's Good2Talk' parent resource on sharing your diagnosis**, is designed to be available in any health or social care setting that can provide a parent with an opportunity to think things through (see 'Opportunities..' diagram on page 20). It provides practical advice in getting ready, telling your child and seeking support afterwards. This is particularly useful for professionals to have on hand when they are providing support in this area. It is important for parents to have good opportunities to think through how and why they might share their diagnosis, but also prepare for the child finding out themselves.

The key messages for parents are:

- Think about the positives and the negatives of sharing your diagnosis
- Find someone you can talk it through with
- It helps to come to terms with your diagnosis
- Think about the child afterwards – what support will they access? Who can they talk to? What can you do to create a supportive environment?
- Prepare and practice what to say
- What to do if the child/young person finds out in an unplanned or abrupt way
- Finding support for yourself

³² Cited by Nam et Al (2009)

Geogory's place project Barnardos have a four page booklet called **Talking to Your Child about HIV for the First Time - A guide to help parents and carers of children who are affected by HIV** (there is also one for parents and carers of children and young people with HIV). They include questions designed to take the parent through the planning process and for the parents to fill in their answers.

Here is a sample

Do you know what your child already knows about HIV?
Where has your child got this information from?
Have you thought about how you are going to explain what HIV is to your child?
Do you know how to explain to your child what effect HIV has on your life and your future?
How are you going to explain to your child how you became HIV positive?
Have you thought about how your child will react to being told you are HIV+?
Have you thought about what questions they might ask you?
How can you prepare for these reactions and questions?
Who might be able to help you explain things to your child?

Positive Parenting and Children have produced a small credit card size booklet called **Sharing something important with your child**. It condenses the main points of what should be considered when planning to share your diagnosis with your child. Parents and professionals have found particularly useful because of its size, simplicity and no mention of HIV. This has meant that parents are more prepared to pick it up and take it home.

Faith In People with HIV, have devised a website designed to be used a tool for parents wanting to guide their child, in a safe and age appropriate way, as they tell them about HIV.

The Include Project, Children's Society have resources for services supporting young carers in families affected by HIV. The young person who has become aware of their parent's or sibling's HIV status may increase their physical and emotional caring responsibilities and may need support in this respect. Particularly useful are: **Supporting young carers in families with HIV – Information for HIV professionals, The Whole Family Pathway**, a free online resource for all practitioners working with young carers and their families and **The Refugee Toolkit**.

7. **Further resources**

It is essential that good quality information is available to hand in user friendly formats when HIV is discussed. CHIVA has built a resource library where some information resources are available to download or order. The following are very useful websites that will support and update your knowledge. They also have information resources that can be ordered, and can be used to help us combat some of the myths and misconceptions about HIV, sex and relationships as we encounter them in our work.

CHIVA is a network for people providing health care for young people and children living with HIV, and a website hub of information, guidance and support for professionals, parents and young people living with HIV. www.chiva.org.uk

NAM and aidsmap work to change lives by sharing information about HIV and AIDS. NAM provide a comprehensive database for national and international HIV organisations www.aidsmap.com

AVERT provides AIDS & HIV information, including information about HIV/AIDS infection, HIV testing, prevention, global and African information, AIDS treatment and more www.avert.org

NAT - the National AIDS Trust - is the UK's leading charity dedicated to transforming society's response to HIV. www.nat.org.uk

NCB Children and Young People HIV Network – works to build partnerships with agencies and organisations that have an interest in children and young people living with and affected by HIV. The current focus of it's work is transition for young people living with HIV. The network maintains an email bulletin (send a blank email to: join-hiv-news@ncb-lists.org.uk) www.ncb.org.uk/hivn/home.aspx

9. References

A. Asander, A. Björkman, , E. Belfrage and E. Faxelid, (2009) **HIV-Infected African Parents Living in Stockholm, Sweden: Disclosure and Planning for Their Children's Future** Health & Social Work Vol. 14, No. 2 MAY 2009 p107-115

Conway M, Donaghy S and Melvin D (2008) **Talking to children about their health and HIV diagnosis**

Available to download from www.chiva.org.uk/health/guidelines/talking.html

(includes a disclosure grid outlining a knowledge timeline whereby the overall process of explaining HIV to a child is described)

Cree,V and Sidhva, D (2009) **'I want to be like the others' A cross sector needs assessment of children infected and affected by HIV in scotland'** The University of Edninburgh

D. DeMatteo, C. Harrison, C. Arneson, R. Salter Goldie, A. Lefevbre, E.S. Read & S.M King, (2002) **Disclosing HIV/AIDS to children: the paths families take to truth telling** Psychology, Health and Medicine, VOL. 7, NO. 3, 2002 pages 339-356

Kinouani,G, Terspeli,L & Morris,V (2011) **Learning from families living with HIV: UK Family Project Residential Report** UK Family Project

S.L. Nam, K. Fielding, A. Avalosb, T. Gaolathec, D. Dickinson and P.W. Geisslere. (2009) **Discussing matters of sexual health with children: what issues relating to disclosure of parental HIV status reveal** AIDS Care Vol. 21, No. 3, March 2009, 389-395

NAM (2008) **HIV and Stigma** NAM

J. Patterson & R. Blum (1996) **Risk and resilience among children and youth with disabilities** Archive of Pediatric Adolescent Medicine, 150, 692–698.

R. Ostrom Delaney, J.M. Serovish & J.Y. Lim (2008) **Reasons for and against maternal HIV disclosure** AIDS Care vol 20, no 7 876-880

The People living with HIV stigma index (2009) **Give stigma the index finger – Scotland report** <http://www.stigmaindex.org/50/analysis/uk.html>

Positive Parenting and Children (2011) **It's time to talk – 4 young people's stories of how HIV has affected their lives** PPC, London

Prost, A. (2008) **A review of research among Black African communities affected by HIV in the UK and Europe**. Occasional Paper 15, Occasional Paper 15. MRC, Glasgow.

M.J. Rotheram-Borus, D. Flannery, E. Rice, P. Lester (2005) **Families living with HIV**. AIDS Care 2005, 17:978-987.

A. de Ruiter, D. Mercey, J. Anderson, R. Chakraborty, P. Clayden, G. Foster, C. Gilling-Smith, D. Hawkins, N. Low-Beer, H. Lyall, S. O'Shea, Z. Penn, J. Short, R. Smith, S. Sonecha, P. Tookey, C. Wood and G. Taylor, (2008) British HIV Association and Children's HIV Association guidelines for the management of HIV infection in pregnant women HIV Medicine (2008), 9, 452–502 British HIV Association

Skyler T. Hawk **Disclosures of maternal HIV infection to seronegative children: A literature review** Journal of Social and Personal Relationships 2007 24: 657



UK Family Project / Parenting & Children (PPC), 49 Effra Road, Brixton, London, SW2 1BZ
Tel: 020 7738 7333 Fax: 020 7501 9382 PPC is a registered charity. Charity number 328427
and a company limited by guarantee. www.ppclondon.org.uk