



The Children's HIV Association

Open And Honest Practice When Working With Children

Quality Standard:

Author: Amanda Ely

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Definition of key terms:

Living with HIV: someone who has HIV infection.

Affected by HIV: one or more close family members has HIV, but the person themselves does not.

Disclosure: Definition; the act of revealing or uncovering. 'Disclosure' as a term in other circumstances has some negative associations and implies an event. In Paediatric HIV too the term 'disclosure' is used to cover a number of things including telling a child about an HIV diagnosis' but also sharing the HIV diagnosis to others. In this document the term 'disclosure' will be used to cover the process of building up knowledge about an HIV diagnosis with children, covering aspects of conversations and understanding before and after the naming or telling event. Increasingly now this is referred to as "naming" HIV to children, in an effort to reflect this "process" rather than a disclosure event. This document will use the term naming HIV on the whole, but at times refer to disclosure when needed for clarity.

UNCRC: United Nations Convention on the Rights of the Child, 1989.

WHO: The World Health Organisation (referred to in this document in relation to the WHO guideline on HIV disclosure for children up to 12 years of age, 2011)

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Introduction and Process**Introduction**

1. This standard considers the way in which work is undertaken with children and young people living with HIV. It is concerned with how conversations and explanations about HIV occur, with its main aim being to promote practices which work towards greater openness and honesty in conversations about HIV with children at a younger age and enhance the best interests and wellbeing of the child.

The issue of children and young people s' knowledge of their own HIV or that of a close family member has historically been a key practice issue for services and continues to be consistently raised by professionals as a key challenge.

Although the standards' main aims are to support the working practice of non health professionals , it is hoped that the discussion of issues, presentation of arguments and aims of the standard are relevant for health professionals too, and that the standard will serve to influence current HIV disclosure practice in paediatric HIV. Collaborative working relationships (between health and social care) being integral to effective work with children and their families who are living with HIV.

The standard will enable professionals in a range of organisation contexts to consider their current organisational practices and develop these to work towards shared aims and objectives in this area, to achieve greater openness and honesty in work with children, concerning their knowledge and understanding of HIV and how it affects them personally.

Process

1.1 In March 2011 a practice sharing event was organised by CHIVA and the UK Family Project (a collaborative project managed by Positive Parenting and Children, (PPC)). It was attended by over 50 professionals working in the voluntary, statutory and health sectors with children and their families living with HIV. At the event, questionnaires were completed. The questionnaires asked for information on a range of practice areas. Professionals were asked to provide information on their work in relation to children s' knowledge of their HIV or a close family members.

The range of responses offered identified extensive professional challenges in this area, and most related to parental issues; *"parents reluctance to disclose"*, *"parents resistance /not feeling ready"* *"parents fears, not feeling confident about their children holding information about HIV"*, *"shame and fear of intimidation"*.

Concerns were also raised in the questionnaires about the impact on children in families where there was partial or no knowledge about HIV. *"children having to keep secrets from their brothers and sisters"*, *"children being asked why they have to medicate daily."*

The questionnaires also revealed the extensive work which takes place around the naming of HIV in families, undertaken by professionals in the range of organisations represented on the day.

1.2 A working group was compiled from professionals attending this event who were interested in this issue and who would come together to meet and discuss the aims of the standard and be available to consult, and provide feedback and advice throughout the process: The working group consisted of:

Kate Brown:

Specialist HIV social worker, Body Positive, Manchester

Sheila Donaghy:

Nurse consultant paediatric HIV, St Georges Hospital, London.

Jill Hellings:

Social work team leader, Gregory's place project, Barnardos, Manchester.

Diane Melvin:

Consultant clinical child psychologist, St Marys hospital, London.

Vicki Morris:

UK family project manager, held within PPC London.

Michelle Overton:

Women and childrens worker, Faith in people with HIV, Leceister.

Nimisha Tanner:

Service manager, Body and Soul, London.

(Diane Melvin and Sheila Donaghy were specifically asked to be involved in the work with the working group to, offer advice and guidance and to ensure that perspectives from within health services were included in the work)

1.3 Commissioners were consulted for their views and interest in a standards document being produced and information gained from them on how this may be of use in the commissioning of services. Standards are widely used in commissioning, and with the increased emphasis on “outcomes and impact”, there is likely to be an increased pressure on services to prove that the work they do with children and their families has identifiable benefits and leads to positive outcomes. Standards are being used to assess this evidence base and are seen as a means to improve quality.

1.4 This standard has also been influenced by findings from the Swedish model which has been developed by HIV social workers and paediatric HIV health professionals from the The Swedish National Competence centre for HIV-infected children and young adults, Karolinska University Hospital, Stockholm.

This model was presented at the CHIVA conference in May 2011, <http://www.chiva.org.uk/professionals/health/events/previous/conference11/powerpoint.html#cralsgard>

Some of the members of the working group visited Sweden to learn more about this model from the HIV specialists at Karolinska University hospital in Stockholm.

Some key points about this model:

- HIV has been spoken about openly, regardless of the child’s age, with all new patients since 2009. The child and parent/carer are spoken to about HIV openly at each clinic appointment.
- The key aims of the model are to reduce anxiety and give hope to children growing up with HIV.
- All questions asked by children are given honest answers.
- Attention is given to language use to ensure it does not stigmatise HIV.
- Children are not told they cannot tell other people they have HIV. But they are asked who they would want to tell. This is then explored, and the children take part in the decision made as to whether telling would be a good thing to do at that time.

A key learning point for the group following this visit was the emphasis placed on children s’ rights in this approach. There were clearly some context differences, and a significantly more extensive system of support provided through government agencies was available to children in Sweden such as a social worker being present at each clinic appointment and extensive access to HIV

“education schools” (similar to the CHIVA support camp) for all children with HIV over the age of 10.

However some key principles were very relevant regardless of the difference in context:

- The important roles that professionals can take in acting to reduce the stigma associated with HIV. (which conversely highlights how professionals can unwittingly support stigma around HIV)
- The importance of recognising children’s rights.
- How effective collaborative work between health and social care professionals can take place.
- Evident confidence in the multi disciplinary team in modelling openness around HIV to families, and confidence in their capacity to support families on this issue.

2. Defining statements

2.1 Social care and support to children who have HIV and those closely affected by HIV should strive to place the child at the centre of their work. A child rights approach is taken, when as a starting point the child is respected and viewed as competent. The child is recognised as having rights as an individual, with a right to knowledge and inclusion in decision making about matters which are important in their lives. They are seen to be in a unique position to understand their own needs and be given opportunities to participate meaningfully in discussions and decisions concerning their health and well being, relative to their stage of maturity and development.

2.2 This standard promotes practice whereby all those working with children develop open and honest relationships about the nature of their work and the reason for their involvement. Professionals should aim to create an environment where HIV is normalised (treated as another chronic illness of childhood would be) and de-stigmatised.

2.3 Stigmatising attitudes associated with HIV which often shut down conversations about HIV in other spheres of the child s’ life should not be mirrored in health and support care settings. Instead organisations should model openness and confidence in discussions around HIV and open conversations about how HIV affects the child and their family are encouraged.

2.4 A child should have conversations which increase their knowledge and awareness about their health and the name of their virus as HIV, in line with their cognitive and developmental capacities.

2.5 Whilst discussions about health and HIV as a diagnosis may be led by health, social care and support organisations are in a strong position to increase knowledge and understanding, and provide support on how to manage the impact of living with HIV in everyday life. Collaborative working between health professionals and others working with the child and their family promote open and honest conversations around HIV, sharing appropriate information about levels of understanding around HIV and identifying on going needs.

2.6 Children affected by HIV in their family are also recognised as benefiting from having HIV named to them, in line with their cognitive and developmental capacities. Opening up conversations about HIV in the family serves to provide opportunities both for ongoing support to the child and also for discussions around their concerns about future care. Support organisations are in a strong position to lead on this work and advocate for the needs of the child affected by HIV.

2.7 Confidence in practice is demonstrated when professionals strive to increase the normalisation of HIV by placing it in the context of living with a chronic condition.

2.8 Organisations explore and agree upon conversations with children about HIV, which promote open, honest, and up to date discussions around HIV.

3.Rationale

Here follows a discussion which considers some of the issues concerned with children having knowledge about HIV in their lives. The rationale for this standard is reflected in the materials explored here, as well as the practice experiences of all those involved in work on this standard.

3.1 *“A protective stance gradually needs to give way by allowing children to determine what happens to them on their journey to competent adulthood. They need to acquire knowledge and experience life. This empowers children.” (1).*

True well being, it is suggested, will require a measure of control over ones’ life. This can be achieved by acquiring life skills and achieving autonomy (1). As such children must be empowered to make their own decisions, with certain parameters. This process is one of “trusting, affirming, and building self esteem in children” (2).

It can sometimes be a challenge to recognise the individual rights of the child in Paediatric HIV because of the family dimensions of HIV . Practice has often been lead by a highly protective stance by professionals and parents alike, with concerns about children’s ability to cope with the knowledge of their HIV status. As the prognosis for children with HIV has improved dramatically with treatment advances, so has the need for children to be better equipped with knowledge about their own HIV in order to be involved in and manage the health and social impacts that HIV brings.

3.2 The professional practice of “disclosure of HIV to children” developed in both health and social care has as its starting point, the position of a child not knowing they live with HIV and such a context can serve to reinforce a sense of anxiety associated with HIV.

Since 2008 there have been Children’s HIV Association (CHIVA) guidelines in place, for health care settings, which state that children should have had HIV named as the virus they are living with *ideally* before they begin secondary school (3). An audit was undertaken in 2007 which found that of the respondents, 68% of children aged 10 and over had had HIV named to them as the virus they lived with -12 being the median age when this took place. However 16% were unplanned disclosures. (4)

As such there remains a context whereby most young children (under the age of 11) do not know the name of their diagnosis, and there are still a few older children who have still not had HIV named to them.

3.3 It is known that significantly higher numbers of children closely affected by HIV have not had this information told to them, (through the broad practice experiences of those involved in work on this standard). This data is much more difficult to collate, and the overall number of children who are closely affected by HIV in the UK is also not known. But we know this is a considerable group, likely to be upwards of 20,000.

Although the presentation of arguments is different here, as an individual child s’ **right** to know the health information of another person, be it their parent or sibling may not be arguable. However these children are included in the WHO guideline on disclosure (2011) (6). These conclude with a key recommendation that children affected by HIV, of school age, should be told the HIV status of their parents/care givers. This is seen as **beneficial to their well being**, with concerns raised

about the evidence of the adverse effects of the lack of disclosure. (6) Clearly the affects of non disclosure of HIV on the experience of family life/relationships are going to be experienced by the infected and affected child alike. Where spheres of secrecy around HIV are built, and concerns and anxieties about health which children are likely to become aware of, will remain un-addressed or supported.

There is also the very real prospect of children (both infected and affected)- becoming aware of HIV through access to information via the Internet. Unplanned disclosures occurring through internet searches, for example of medication types, are a further compelling reason for ensuring children are told about HIV in their families, enabling attention to the support and inclusion needs of these children and young people.

3.4 Members of the CHIVA projects team have worked directly in a range of settings with young people who have HIV for many years, the following accounts are commonly heard experiences which young people have described concerning how they learnt they had HIV. These are supported by accounts given by the members of the working group who have extensive experience of working with children and young people with HIV:

Young people who were told around the age of 12 (as current UK practice guidance advises) tend to have a distinct clear memory of this. Although attention is given to this being a process of building information up gradually over time, for the young person the naming of HIV still tends to be remembered as a key event. Many young people can describe that moment in clear detail, including where they were, who was there, and recount the emotions they experienced at the time, along with the fears frequently described. Young people who were told at a younger age tend to have a much more vague memory of this, and clearly their understanding of HIV and the wider social responses to it, are much less formed. When asked how old they were, their response tends to be 'I've always known'. HIV can in these cases be seen as a far more normalised experience as something they have grown up always knowing. For a much younger child HIV is mainly going to simply be three letters with little significance. The emotional and psychological adjustment experience that the older young people have described, which can be traumatic, occurring when they were told they had HIV is not something the young people who were told at a much younger age describe.

3.5 Parental concerns were cited in the audit as the overwhelming reason for delaying the "disclosure process". (These parental concerns were also the challenge most commonly identified in the questionnaire feedback gained from the practice sharing event, which was described above in the process information.)

Arguably tensions can arise between the need to build supportive relationships with parents/carers and appreciate the issues which multiple HIV diagnosis within families can present, and recognising the needs and rights of children as individuals. This tension may have lead to in many respects "the family" becoming the patient in paediatric clinics, whereby the needs and rights of the child may not always be the foremost consideration in decision making, and parents views/needs strongly influence practice around the care and support of children with HIV.

3.6 There must be recognition of parents entitlement to make decisions for their children provided they do not act against their best interests. However we need to ask, do parental fears and anxiety about their children having knowledge about HIV go against what is actually in the child s' best interests in many cases? And are parents anxieties based on their own experiences of being told about their HIV? It is important to consider the child s' need to understand what it means to live

with HIV currently, and how best can they be supported to understand this as something which has always been a part of them and be equipped with tools they need to live well with HIV.

3.7 Human Rights Watch (5) compiled five reasons why children should be told that they live with HIV.

Three of these reasons are particularly compelling here:

- Children who are told about their status learn that it is acceptable to talk about HIV, which helps address the stigma surrounding the disease. By not telling a child that they are HIV-positive, the stigma of the illness gets transmitted to the next generation, and often this results in children feeling ashamed and isolated.
- Children who are told about their status in a supportive way tend to be more self-confident than those who have not been told, according to the American Academy of Paediatrics. The Academy has also stressed that a "conspiracy of silence" may isolate children from potential sources of support and undermine trust between adults and children.
- Children have the right to health information under the Convention on the Rights of the Child. If children are not told their status but are mature enough to understand and appreciate it, their right to health and information may have been violated.(5)

3.8 The World Health Organisation (WHO) have recently produced guidelines which recommend children being told that they have HIV by the time they are school age (and this is defined as 6 encompassing all children under the age of 12). The guidelines were produced after an intensive 3 year process, where the guideline working group undertook an extensive literature review to explore the evidence to develop the recommendations in the guideline. (255 studies from a wide range of countries were examined) The group also drew on their own extensive professional experience in a range of different contexts, working with children and their families with HIV.

The recommendations state that "*children of school age should be told their HIV positive status: younger children should be told incrementally to accommodate their cognitive skills and emotional maturity, in preparation for full disclosure*".(6) Further more "*children of school age should be told the HIV status of their parents or caregivers: younger children should be told incrementally to accommodate their cognitive skills and emotional maturity*" (6)

3.9 Attention is paid in the WHO guideline to an understanding of child development, studies were considered which looked at children s' capacity for understanding illness and taking care of themselves. Various studies were cited which suggested this takes place between 6 and 8 years (in a typically developing child) and that by the age of 8 or 9 most children were able to understand the concept of death, and half of 5 year olds had a partial or full understanding. (7) This evidence on competency is important when considering children s' capacity for coping with and understanding information relating to their HIV, or living with someone who has HIV.

Context concerns and challenges are acknowledged in the guideline, parents feelings of shame and their fear of inadvertent disclosure and stigma tend to discourage them from revealing their own or their child s' HIV status.(8) The guideline also points to research which indicates that concealing HIV status, however, may lead to or exacerbate depression, worry and other negative mental health outcomes, potentially interfering with treatment and affecting family life, including parenting ability and the child s' social and academic life, e.g. school performance. (9,10,11,12)

4.Normalisation of HIV

4.1 Arguably considerable time has been spent learning and establishing professional HIV care and support as a “specialism”, which perhaps has led to it being seen as different, and requiring different types of responses, services etc. Acknowledging the need for children and young people who are growing up with HIV to accept HIV and to continue to feel “normal” and not “different”, it is important that professional responses support the normalisation of HIV.

4.2 Children living with HIV should not be subject to health and social care responses so markedly different to those responses given to children living with other chronic illnesses.(particularly so now most children and adults “live with HIV” as opposed to die from it) There is a need for professionals to support a normalisation of HIV, in an effort to address the persistence of stigma, which is supported by ongoing practices of avoidance of open conversations about HIV in both health and social care settings.

4.3 Such practices can be viewed as mirroring spheres of secrecy which already surround HIV in many communities, and, without meaning to, can support a context where HIV is seen as very different and ultimately something to fear. The child will then take on this fear and therefore not be sufficiently equipped with the tools they need to live well with HIV.

5.Policy and legal context

5.1 In 1991 the UK government ratified the UN Convention on the Rights of the Child (UNCRC, 1989). Many of the principles set out in this document were enshrined in UK law in the Children Act 1989 (and further developed in the Children Act 2004).

UNCRC key principles relevant here:

- The best interests of the child must be the primary consideration in all matters affecting the children (article 3)
- Children have the right to participate in decisions that affect them (article 12)
- Every child should have access to information and material from a diversity of national and international sources, especially those aimed at the promotion of his or her social, spiritual, and moral well being and physical and mental health (article 17)
- Children have the right to the enjoyment of the highest attainable standards of health (article 24)

5.2 The Children Act (1989) and (2004):

The Children s’ Acts have led to a more rigorous child rights approach within both health and social care. The Children Act 1989 was key in establishing the welfare principle, in that all decisions made about the child must be led by concern for their best interests. The use of rights ensures that the child’s interests are not neglected. (1) A child rights approach asserts that children, whatever their age and circumstance, can provide valuable perceptions that can improve their clinical care. (1) But for this right to be fully appreciated, the child needs knowledge with which to make decisions and provide perceptions.

5.3 Gillick competency and Fraser guidelines refer to a legal case which looked specifically at whether doctors should be able to give contraceptive advice or treatment to under 16-year-olds without parental consent. But since then, they have been more widely used to help assess whether

a child has the maturity to make their own decisions and to understand the implications of those decisions.

Lord Scarman commented in his judgement on the Gillick case in 1985:

“parent right yields to the children s’ right to make his own decisions when he reaches sufficient understanding and intelligence to be capable of making up his own mind on the matter requiring decision” (13)

5.4 This legal judgement has secured in health and social care practice the need to consider the competency of the children professionals work with. Importantly it also addresses the need for the children s’ views to be the primary consideration in decision making, which do over ride parents rights to make such decisions for the child, when the child is considered to be sufficiently competent. Their capacity to understand information which pertains to them, and their capacity to be involved in making the decisions which affect their lives

6.Aims and benefits

Here follows the aims for this standard and the benefits.

6.1 AIM: Within any service for children and young people living with HIV, trusted and confident relationships are developed with professionals which include open conversations about HIV.

BENEFIT: A child provided with knowledge about HIV as a health condition increases their coping strategies around managing the impact of HIV on their lives, whether they are infected or affected by HIV. Their wellbeing is further enhanced if they are fully aware of the nature of the organisation they are involved with so trusting relationships can be developed and effective support provided.

6.2 AIM: Work with children and young people reflects a “child rights approach”, where the “best interests of the child” is the paramount concern in all work with children and the need to empower children is recognised. Children are recognised as having individual rights.

BENEFIT: Children are empowered to be involved in the care and support provided to them and are effectively equipped to cope with HIV knowledge.

6.3 AIM: Build effective collaborative relationships between health and other social care and support services to ensure an holistic, comprehensive and shared approach to care and support for families.

BENEFIT: The level of HIV knowledge of individual children is known between the core professionals who work with them in order to avoid inconsistencies, and enables a collaborative plan to enhance the child’s wellbeing and care . Where there is a need to advocate for the needs of a child to receive information this can be identified and acted upon.

6.4 AIM: To reduce negative and stigmatising associations and normalise HIV through open and up to date conversations on HIV being thoroughly established throughout organisations working with children and young people.

BENEFIT: Confidence within staff teams to lead conversations about HIV, and model this openness to families. Opportunities for staff teams to have up to date knowledge and understanding of how HIV impacts upon children and young people helps builds their own confidence and works to reduce the stigma around HIV. Professionals are active and confident in modelling openness around HIV. This in turn will have benefits for the child and family. Conversations around HIV in organisations are free from stigma.

7.How to meet the aims of this standard

Below are a range of different indicators which are presented as particular practice responses which can help you work towards addressing the aims of this standard for “open and honest practice when working with children”.

Organisations are very different. It is important to work out which goals are most relevant and important for you to work towards. Initially it will be important to assess your organisation in relation to the areas outlined in the core standard. See the appendix for guidance on carrying out an organisation assessment with the standard.

Once these core standards have been assessed and met the goals for the developed standard can be worked towards.

7.1 Core standard

Indicators to meet this standard at a basic level:

- Policy exists which outlines how all discussions about HIV are approached in the organisation and outlines key aims to develop and improve knowledge and understanding of HIV among all user groups.
- Policy exists which outlines how organisations will respond to direct questions from children and young people concerning HIV and how it affects their lives. Policy reflects the need for honest answers to be given to children s’ questions.
- Staff are encouraged to speak openly about HIV. Staff receive training which ensures their knowledge and understanding of HIV is correct and current and addresses confidence in speaking about this.
- Staff in the organisation use language which does not serve to support stigma around HIV. (HIV is not spoken about as a secret or something which must be hidden)
- Initial assessments on families include questions which explore who knows about HIV in the family.
- Care planning / work plans with families include work which will address improved knowledge and understanding of HIV in the family among the children and young people, and support improved communication within the family.

- The organisation is able to offer support to parents/carers in telling their children about someone close to them having HIV. Before, during and after the naming of HIV in the family the organisation are equipped and competent in providing ongoing support and guidance.

7.2 Developed standard:

Indicators to meet this standard at a developed level:

- Professional confidence in leading conversations with children, young people and their parents which are open about HIV is well established in the organisation.
- Children and young people have structured and frequent opportunities to discuss HIV. Organisations do not shut out conversations about HIV in any of their services offered. They have access to up to date information about HIV and are supported in managing the impacts of HIV in their daily lives.
- Children and young people who have HIV can access separate spaces to talk about issues related to living with HIV, both individually and together as a group.
- Clear evidence of young people taking control over decision making in relation to the impacts of HIV on their lives is demonstrated and they are supported and encouraged to do so by the organisation.
- Children are given meaningful opportunities to have their say and become involved in defining the way services are developed and run. There is clear evidence of children s' empowerment and their views and opinions are regularly sought.
- Professionals actively encourage and support parents in building their confidence and skills in having conversations with their children on how HIV affects their lives. Parent/carer confidence in holding conversations with children and young people which are open about HIV is demonstrated.
- Multi agency approaches are integral to work with children and their families living with HIV. Collaborative working practices are well established between the voluntary sector, health and other social care services. A flow of appropriate information exists between the core professionals working with children and their families, and this is known to the child and family. Collaborative working takes place between these services, planning , developing and supporting the ongoing open conversations about HIV to children as they grow up.
- Shared use of language, which does not serve to stigmatise HIV, is applied between health, social care, and voluntary sector organisations. Whereby an open approach to HIV and conversations about HIV are firmly established.

References

1. Hagger L (2009) *The child as vulnerable patient: Protection and empowerment*. Ashgate publishing limited. Surrey.
2. Hymas, JL., "Do children have rights? citing Cullen. S Empowering children (1999)
3. Conway, M. Donaghy, S. & Melvin, D. (2008) Talking to children about their health and HIV diagnosis. CHIVA.
4. Donaghy, S 2008 <http://www.chiva.org.uk/professionals/health/audit/audits/disclosure08.html>
5. <http://www.hrw.org/node/94635To>
6. http://www.who.int/hiv/pub/hiv_disclosure/en/index.html
7. Lansdown R, Benjamin G. The development of the concept of death in children aged 5–9 years. *Child: Care, Health and Development*, 1985, 11(1):13–20.
8. Letteney S, Heft LaPorte H, Deconstructing stigma: Perceptions of HIV seropositive mothers and their disclosure to children. *Social work in health care*, 2004,38 (3):105-123.
9. Armistead L et al. Disclosing HIV status: Are mothers telling their children? *Journal of Paediatric Psychology*,2001, 26(1):11–20.
10. Lee MB, Rotheram-Borus MJ. Parents' disclosure of HIV to their children. *AIDS*, 2002, 16(16):2201–2207.
11. Murphy DA, Marelich WD, Hoffman D. A longitudinal study of the impact on young children of maternal HIV serostatus disclosure. *Clinical Child Psychology and Psychiatry*, 2002, 7(1):55–70.
12. Ostrom RA et al. The role of stigma in reasons for HIV disclosure and non-disclosure to children. *AIDS Care*,2006, 18(1):60–65.
13. http://www.nspcc.org.uk/inform/research/questions/gillick_wda61289.html,

Appendix 1

A series of toolkits and practice handbooks were produced by the UK family project, managed by PPC London. The "Its good to talk" series offers a range of tools and guidance for professionals working with children and their families with HIV on the topic of communication. Working towards increased sharing of and communication around HIV in families. See these workbooks on PPC's website: <http://ppclondon.org.uk/uk-family-project/#>

Appendix 2

Workshop format to enable an organisation to undertake assessment of current practice in relation to openness and honesty in work with children around HIV.

Form templates to record current assessment and action plans to work towards meeting the aims of the standard.

(*To Follow)