

Standards and Model for Psychological Care for Children and Young People Living with HIV Infection (Summary)

This summary about effective psychological support in paediatric health care services for children and families with HIV is based on the principles behind the standards for psychological care: a document first produced by Paediatric HIV Psychology Group in Oct 2014.

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Standards at a Glance

Standard 1: Access to Psychological Support

All children and young people, regardless of their HIV status, should receive care which promotes their psychological wellbeing. In the UK, all children living with HIV (CLWH) regardless of gender, ethnicity, age or place of care should have access to psychological services. Psychological care should be integrated into physical health services and include those with knowledge of communication and adjustment in chronic childhood health conditions as well as providers who are aware of the unique needs of this client group. An optimal psychology service provision requires a minimum of 0.2 WTE per 20 patients, additional WTE may be added to meet the needs of complex patients.

Standard 2: Engagement and Participation of Children, Young People and Their Families

Services and organizations providing emotional support for children living with HIV (CLWH) should provide approaches which facilitate on-going engagement and changing participation of the child and family throughout the health care journey. Approaches enhancing children and young people's participation should take account of age, maturity and capacity and be sensitive to confidentiality concerns.

Standard 3: Identifying Developmental and Psychological Needs

Children living with HIV should have regular reviews to identify any difficulties early which would benefit from further assessment or intervention both to help enhance coping with their condition as well as enabling access to appropriate support, when needed, which promote learning, communication, emotional and mental health, independence and on-going life skills.

Standard 4: Support for Knowledge, Understanding and Sharing Information about HIV

Psychological and developmentally appropriate approaches should be available to all CLWH and their carers aimed at increasing knowledge and understanding of HIV and its effects to enable appropriate participation in decisions about personal health and treatments, enhance awareness of responsibilities around onward transmission and share strategies about how and when to safely share the diagnosis with others.

Standard 5: Psychological Approaches to Managing Treatment

Psychological influences from both the CLWH and also their family or home situation, should be integrated into discussions and plans aimed at supporting medicine taking and longer term adherence to treatments. Timely access to more specialist psychological interventions should be available if difficulties arise with starting, continuing or coping with any consequences of treatments.

Standard 6: Promotion of Psychological Wellbeing in Adolescence and During Transition between Paediatric and Adult Services

Psychological approaches should be integrated into health care throughout the transition process and aimed at a successful engagement with an appropriate adult HIV service. Providing appropriate and timely psychological support to enhance coping with the many changes in personal and social development occurring during this time should focus on enhancing independence and identity as well as support for more autonomous healthcare decision making s and self-management of the condition.

Introduction

“Psychological support: is any form of support which is aimed at helping people living with HIV to enhance their mental health and their cognitive, emotional and behavioural well-being” (BHIVA 2011).

The impetus for a document about psychological support for children and families living with HIV arose during discussions in the production of psychological standards of care for adults with HIV infection (BHIVA 2011). Whilst recognising that emotional and psychological support is equally important in the care of children and young people with HIV infection, as it is for adults, developmental and family factors influence the nature and timing of effective approaches.

This summary provides a background to the general principles behind the standards of psychological care for children and young people with HIV (CLWH) and their families and introduces a model of service delivery as well as the six key standards for effective psychological care. Evidence and practices known to be effective in psychological support in other chronic childhood health conditions as well as from HIV populations are presented in this document (DOH 15, Mercer et al 2015, and Kings Fund 2016). The focus of this document is on paediatric health settings seeing CLWH less than 19 years of age with perinatally acquired HIV; these are the majority of those seen in paediatric HIV health settings in the UK (CHIPS 2014). However many of the recommendations may be appropriate for children and young people where HIV infection was acquired in other ways and for HIV services in community as well as health settings. They may also raise awareness of the emotional needs of those children affected (but uninfected) by the presence of HIV in the family and help to guide and refer families to other appropriate services for any affected children who need more psychological support.

The essential role played by all health and care professionals in supporting the emotional and psychological wellbeing of CLWH and their families is recognised as key to comprehensive and effective support. This document also aims to clarify the additional role and benefits that Practitioner Psychologists can provide within the multidisciplinary approach. Practitioner psychologists are those with a relevant post graduate psychology qualification and in paediatric health settings in the UK this is usually provided by clinical psychologists with experience of child and family work (BPS 2008: PPN). A model of service delivery is presented and is adapted from one used in other paediatric health conditions (Kazak 2006). It illustrates how general and specialist psychology support should be proactive and collaborative to meet the continuing and changing needs of all attending a paediatric HIV service. Key areas of psychological care are documented as **Standards** for all those involved in the health care of CLWH.

The recommendations in this document are intended for those who commission services as well as those delivering care to children, young people and their families living with HIV. Ideas discussed here and in the more detailed standards document may also help inform CLWH and their families about effective psychological approaches which help at different times.

Psychological Approaches in Paediatric Health Conditions

'....maximise health outcomes, minimise the emotional consequences of living with chronic disease and improve quality of life for children, young people and their relatives' (Duff & Bryon 2005)

National Service Frameworks (NSF) and documents from the National Institute for Clinical Excellence (NICE) have frequently raised awareness of the importance of addressing psychological dimensions in approaches to patient care including those for children and families (e.g. DOH 2004, NICE 2009). However whilst there is increasing evidence to suggest the effectiveness of psychological approaches in paediatrics, there remains wide variation in the amount of Practitioner psychology time available in different clinics both to general and specific services (BPS/PPN document 2008).

Chronic illness or physical health conditions affect between 10-30% of the UK child population (Kush & Campo 1998) and services which address psychological aspects of care for children show enhanced later outcomes, both medical and psychological (DOH 2015, Kings Fund 2016). Recent papers on paediatric psychology services emphasise that multidisciplinary, proactive and consultative models of care underlie effective psychological support and differ from the referral and diagnostic approaches found more typically in Child and Adolescent Mental Health Services (Jacobs, Titman & Edwards 2012, Mercer et al 2015). Proactive approaches that enable timely interventions and anticipate and assess vulnerabilities in order to prevent later psychological difficulties have been found to be effective in many chronic conditions such as diabetes, cancer and asthma. (Edwards & Titman 2010, Salmoun –Daly et al 2012). Developmentally appropriate communications and family and systems focused approaches are also found to be fundamental to this psychological care.

Whilst most children and families facing serious paediatric illnesses are essentially ordinary families facing extraordinary stressors, children with chronic health conditions are at higher risk for behavioural and emotional disturbances compared to healthy peers (Kazak 1997, BPS/PPN 2008). Difficulties in the processes of adaptation and coping with the effects and demands of the condition and its treatments appear to underlie many of these disturbances. It is often the complex interaction of protective as well as risk factors from personal, environmental and experiential influences that influence processes associated with coping and adjustment and the choice of appropriate interventions and support (Varni & Wallander 1998, Kazak 2006). Those conditions which result in functional impairments or social isolation and have implications for educational and later employment opportunities also place the individual at greater risk for emotional and behavioural difficulties (Kings Fund 2016). In chronic conditions, continuity of psychological care over time is important as it helps keep in mind those individuals who generally manage well but require extra input at specific points as well as emphasising that attention needs to be paid to changing developmental processes, such as understanding and family relationships, as well as reacting to events.

Background to Paediatric HIV in the UK

I. Context

In 2011 there were approximately 80,000 people living with HIV infection and receiving care in the UK. Only 3% of those were under the age of 24 and only 1% under the age of 15 (NAT, 2012). The Collaborative HIV Paediatric Study (CHIPS) reported 905 cases of children under 18 years with HIV infection in UK and Ireland at the end of April 2016. 93% of these cases were known to be infected through mother to child transmission. 78% of this paediatric population are first generation black African with about a half born in the UK (CHIPS Annual Report 2015/16). Most CLWH live within their biological families, usually with one or both of their parents.

In the UK, HIV is now considered a chronic lifelong condition with most children receiving health care every 3-4 months on an outpatient basis (Lyll, Riordan & Williams 2010). Psychological support to CLWH is increasingly focussed on managing medicines, understanding the diagnosis and any consequences on health or functions of living with HIV whilst coping with ordinary life demands and age changes. There are now fewer acute or inpatient illness episodes, fewer cases of children with severe neurodevelopmental difficulties and support for end of life or bereavements are less a focus for services. (Bamford & Lyll 2015). A diagnosis of HIV still generates some negative, secretive and stigmatising attitudes from wider society and the numbers of CLWH who have experienced loss and change is higher than in the surrounding child population.

Significant improvements in long term survival rates and a reduction in perinatal transmission of HIV have resulted in the UK cohort of CLWH getting older and by 2014 three quarters were aged 13 years or over (CHIPS 2014). This has led to an increasing emphasis on preparation for future and more emphasis on strategies which encourage independence, self-esteem and autonomy with more self-management of treatments and increasing responsibilities over self-care for sexual and emotional behaviours as well as physical health. Interventions need to consider the role of peers and group activities as well as those focussed on family or professional networks.

In the UK there is a small but notable number of late diagnoses of HIV infection in children, sometimes in children who have recently arrived in the UK from other countries with unknown or complex health and psychosocial histories. This group can present increased challenges to those providing care, including psychology services.

II. Psychological Outcomes in Paediatric HIV

Since the introduction of effective maternal and paediatric antiretroviral medicines and HIV care the international evidence has shown improvements in general neurological and psychological outcomes as well as in health and longevity for those surviving with perinatally acquired HIV (Judd et al 2007). Whilst improvements on global or group measures of cognition and intelligence are being reported in populations with access to early and effective treatments a significant number of CLWH are being

reported with a profile of neurocognitive and/or behavioural difficulties which appear to affect attention, memory and learning and interfere with school progress especially at secondary school and may contribute to emotional difficulties and poor treatment adherence. These weaknesses vary in severity and may be quite subtle. They appear to arise from a complex interaction of early and later health and experiential factors but the underlying biological mechanisms and any treatment effects are still unclear (Laughton et al. 2013, Smith & Wilkins 2015).

Reported levels of emotional, behavioural and psychiatric difficulties being reported in CLWH vary across cohorts studied in different countries with a strong relationship to other co-existing factors such as poverty, level of maternal intravenous drug use, familial predisposition, parental ill-health or death etc. As in the general child population as well as with those with chronic health conditions, adolescence is a particularly vulnerable time with increases in self harming and depression being reported as well as an increase in poor treatment adherence (Malee et al 2011).

Within UK cohorts there are a small number of CLWH with enduring and demonstrable but stable neurodevelopmental difficulties which are often associated with other adverse perinatal factors as well as to the effects of HIV infection (Foster et al 2006, Chavatatana et al 2013). Clinical reports and audits indicate there is also a significant number of children needing support at school and similar weaknesses in attention and memory are being reported as in other cohorts (Krechevsky & Melvin 2010). There have been concerns raised about poor treatment adherence rates, difficulties in onward disclosure and some immaturities in emotional and behavioural development within the adolescent group with perinatal HIV infection. There is at present a comprehensive and longitudinal study underway which compares psychological outcomes from youngsters with HIV to those from a comparable uninfected group (AALPHI: Adolescents and adults with perinatally acquired HIV study). Initial findings from the first year of this study indicate that the older UK perinatal HIV population shows good general outcomes in cognitive processes and levels of anxiety and depression and few differences were found compared with those from the comparison group or to norms from test populations (Judd et al 2016). However more detailed assessments including those to do with specific neurocognitive functions, quality of life, self-esteem and coping are now being collected in this study.

It is becoming imperative to identify and intervene early for any weaknesses or difficulties in order to reduce the future costs, financial as well as emotional, of these on future self-management of the condition and treatment adherence, and enables both successful transfers to adult HIV services as well as ensures future employment opportunities.

Specific Aspects of Paediatric HIV

HIV remains a relatively uncommon diagnosis in the UK among children, and there are a number of factors faced by CLWH which are specific to the condition, although some may be faced by many others living with rare health conditions.

- *Stigma*

All those providing care to families where individual(s) are living with HIV need to consider societal attitudes and associations about the condition. Stigmatizing and negative attitudes still exist about HIV and the need for care to maintain the confidentiality of the diagnosis continues to be a paramount concern for families and providers. Whilst the number of reported adverse consequences for CLWH arising from disclosure of their diagnosis is relatively small, it may be the long-term effects arising from the burden of secrecy and fear about sharing the diagnosis with friends, partners and other family members can result in isolation and marginalization. This in turn has consequences for emotional wellbeing. Accessing extra services, in social, educational and psychological care can also be limited by concerns about sharing the diagnosis.

Being confident in discussions about the diagnosis and having up to date knowledge about HIV is essential for all those involved in the care of CLWH and their families as this helps to destigmatise HIV. It helps too to be clear that confidentiality procedures are in place to protect all who attend a hospital or community service, whatever their condition.

- *HIV as an intergenerational family condition*

Children managing any chronic health condition will be influenced by family and wider psychosocial influences. For CLWH, where HIV has been acquired through mother to child transmission there will also be at least one other person in their family i.e. the mother who also has HIV. Other family members may also have HIV e.g. father, siblings etc. This can place additional stress on an already vulnerable system: for example, inconsistencies in parenting and changing carers due to the physical and mental health or death of parent; increased exposure to loss or illness; the effects of family secrets; or social isolation and lack of personal support around fears that the family HIV diagnosis will be found out (Lwin & Melvin, 2001; Malee et al., 2011).

- *Diversity in experience and background*

In the UK, as well as diversity in health and treatment histories, families of CLWH come from a number of different cultural and ethnic origins, with many children first generation African British (CHIPS). Parents and families have a variety of differing health and spiritual beliefs and children can have had a range of early parenting and care provision. Those families or children more recently arrived in the UK may still be adjusting to relocating to a new country, carer and culture; learning a

new language; separation from significant family members etc. Some may have had traumatic or stressful experiences such as significant family deaths adding to difficulties in adjustment and coping.

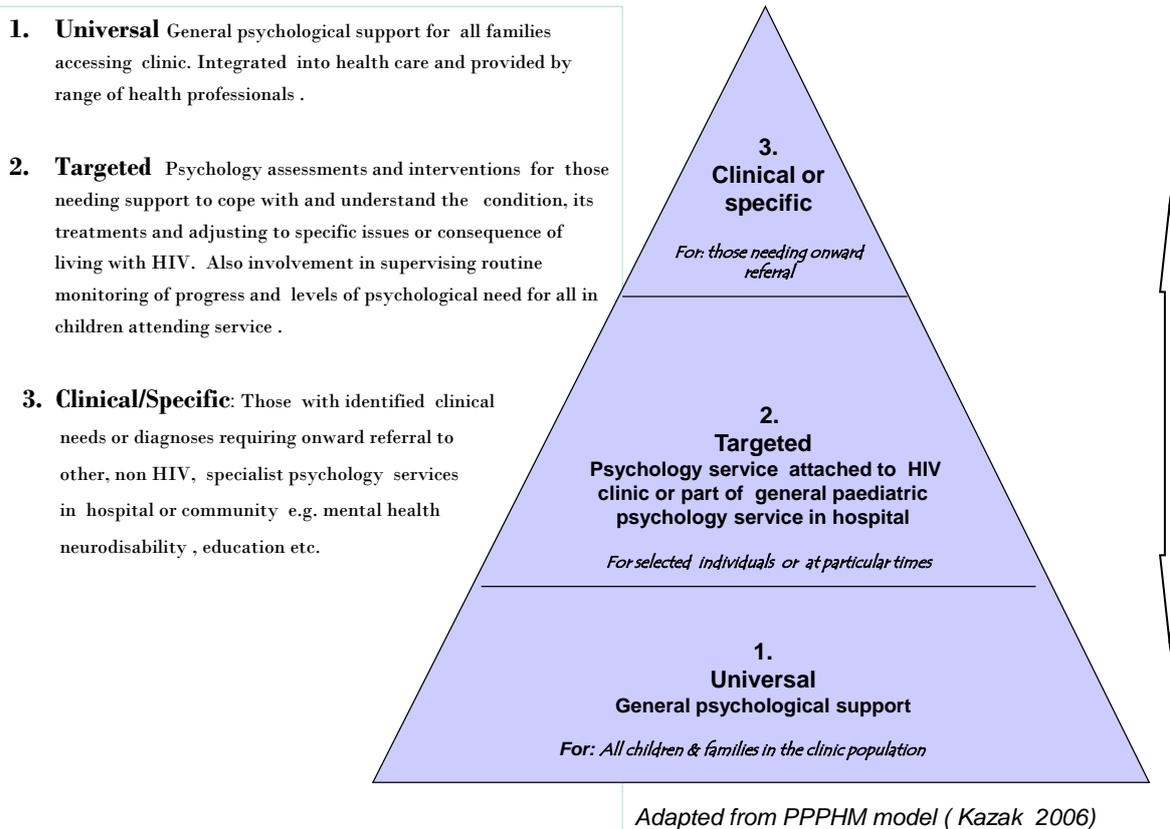
The influence of these factors will be true not only for CLWH but for some of the affected but uninfected children living in families where their parent or sibling has HIV. These affected children are less often seen in health clinics but services need to be mindful of their needs and help signpost to appropriate local services if concerns are raised over their progress or safety.

Psychology Service Model for Paediatric HIV

Any effective psychological services in paediatrics should: *‘demonstrate the delivery of psychological interventions at different levels to improve patient resilience, prevent psychological difficulties, treat complex psychological issues and provide a cost effective service’* (Mercer et al 2015).

Paediatric HIV care in the UK has developed family clinics and family centred care as the basis for holistic, integrated care for CLWH and their families. The family clinic approach now has to adapt to meet the different needs of the increasing numbers of older children and adolescents attending with a wide range of complex psychological issues. Psychology services also need to balance effectiveness with intermittent contact and develop preventative, monitoring and consultative approaches as well as those which react to immediate distress or difficulties and identify those who need onward referral.

The following show a psychology service model where general and specialised approaches can be separated but also linked together. It recognises that at any one time not all of the population will require specialised psychology interventions but all attending the service should be provided with appropriate and sensitive emotional support from providers, whatever their profession or training. This is a model adapted from that developed in paediatric psychology services to paediatric oncology (Kazak, 2006). It is also compatible with the tiered model used in the psychology standards for adult HIV care. (BPS/ BHIVA 2011).



Level 1: Universal

All children and families attending the service, irrespective of complexity of psychological need, should receive emotional support from staff which is aimed at reducing distress and enabling the processes of coping and adjustment to the condition and any treatments.

Level 2: Targeted

A smaller number of the children or families attending the service will require more specialised psychology involvement. This targeted group includes those with unexpected or unplanned needs e.g. individuals where there is an illness episode, a change in the family, or struggling with new medicines or understanding the diagnosis. This group will also include those who need long-term monitoring because of a developmental difficulty, disability or mental health diagnosis. Further it may be that there are particular points on the health journey when psychological reviews or monitoring are useful e.g. baseline for newly diagnosed child, around puberty or secondary school transfer, during transition to adult services etc. These reviews at key times can enable early and timely interventions to be offered if needed.

Level 3: Specific/Clinical

The third level applies to the smallest number in the population: those in need of more specialist assessments or interventions which can best be met by onward referral to a local or specialist service or agency specifically funded and resourced with expertise in more specific assessments or specialist interventions. Such services may be in health, mental health or community and include CAMHS (Child & Adolescent Mental health services), neuropsychology, educational support service, social services or community carers group etc. Most of these would be non HIV statutory services although there may also be agencies within the voluntary sector providing specific support services for CLWH and/or their uninfected siblings.

Clear protocols and referral pathways help identify which specific psychological needs can be met within the specialist HIV team and when more targeted or specialist psychology interventions or provision are required. All those involved in providing psychological support may be at the forefront of responding to any safeguarding concerns so everyone needs to be trained and aware of their statutory duties and appropriate approaches to reduce any further risks to the child.

Appropriate consultation and liaison between service providers at all 3 levels can enhance understanding and management of HIV, as long as individual patient confidentiality is not compromised. For example, staff providing general emotional support at level 1 may benefit from access to guidance or supervision over specific cases or psychological issues. Those working in level 3 services who get a referral of a CLWH patient could benefit from discussion about outcomes and effects of perinatal HIV from someone working in the specialist HIV service at levels 1 or 2. Respecting personal information and the confidentiality of the diagnosis is also essential part of provision. Discussing with CLWH and/or their carers about what health information will and will not be shared with other services and, particularly where they are outside the specialist paediatric HIV team, can help alleviate anxiety about the diagnosis becoming widely known.

Standards for Psychological Care

Six areas have been identified key to the delivery of effective provision for those involved in psychological support to CLWH. These areas are based on evidence and psychology practices used in other chronic conditions as well as from knowledge and consideration of the specific needs of children with HIV. They apply to those delivering general as well as more specialist psychology care. The box below summarises the ethos behind each of these key areas and suggests a standard which should be achieved in all services providing health care to CLWH. Specific details and the up-to-date evidence behind each standard are in the document on the CHIVA website.

- *Standard 1: Access to Psychological Support*

All children and young people, regardless of their HIV status, should receive care which promotes their psychological wellbeing. In the UK, all children living with HIV (CLWH) regardless of gender, ethnicity, age or place of care should have access to psychological services. Psychological care should be integrated into physical health services and include those with knowledge of communication and adjustment in chronic childhood health conditions as well as providers who are aware of the unique needs of this client group.

- *Standard 2: Engagement and Participation of Children, Young People and Their Families*

Services and organizations providing emotional support for children living with HIV (CLWH) should provide approaches which facilitate on-going engagement and changing participation of the child and family throughout the health care journey. Approaches enhancing children and young people's participation should take account of age, maturity and capacity and be sensitive to confidentiality concerns.

- *Standard 3: Identifying Developmental and Psychological Needs*

Children living with HIV should have regular reviews to identify any difficulties early which would benefit from further assessment or intervention both to help enhance coping with their condition as well as enabling access to appropriate support, support, when needed, which promote learning, communication, emotional and mental health, independence and on-going life skills.

- *Standard 4: Support for Knowledge, Understanding and Sharing Information about HIV*

Psychological and developmentally appropriate approaches should be available to all CLWH and their carers aimed at increasing knowledge and understanding of HIV and its effects to enable appropriate participation in decisions about personal health and treatments, enhance treatments, enhance

awareness of responsibilities around onward transmission and share strategies about how and when to safely share the diagnosis with others.

- *Standard 5: Psychological Approaches to Managing Treatment*

Psychological influences from both the CLWH and also their family or home situation, should be integrated into discussions and plans aimed at supporting medicine taking and longer term adherence to treatments. Timely access to more specialist psychological interventions should be available if difficulties arise with starting, continuing or coping with any consequences of treatments.

- *Standard 6: Promotion of Psychological Wellbeing in Adolescence and During Transition between Paediatric and Adult Services*

Psychological approaches should be integrated into health care throughout the transition process and aimed at a successful engagement with an appropriate adult HIV service. Providing appropriate and timely psychological support to enhance coping with the many changes in personal and social development occurring during this time should focus on enhancing independence and identity as well as support for more autonomous healthcare decision making s and self-management of the condition.

Standards 1 and 2 are the basic principles emphasizing that support and timely interventions should be accessible and inclusive to all children attending the specific HIV service and that participation in health care and decision making should be actively encouraged at all ages but be sensitive to age and maturity. **Standard 3** documents the key role of psychology in monitoring any consequences of the condition or its treatments on functions and wellbeing affecting daily life skills and to help identify early those needing extra assessment or support. **Standard 4 and 5** address core processes of disclosure and adherence to treatments which need to be revisited and updated during childhood and adolescence so over time more knowledge and understanding is acquired to help with choices and coping with self-management. **Standard 6** highlights the importance of psychological approaches in the process of transition to adulthood and transfer into adult health services.

These six standards are applicable for those providing general and more specialist psychology care. See below for an explanation of the role of Practitioner psychologists.

Practitioner Psychologists

Psychologists such as Chartered Clinical or Counselling Psychologists best meet the requirements for the Practitioner psychology role in the specialist paediatric and young person HIV service. These chartered psychologists will have a post graduate qualification to a doctorate level in applied psychology and expertise in assessment and a range of psychological interventions across the life span. Within the above service model, Practitioner psychology services would be in level 2 in terms of expertise and governance for a specialist paediatric HIV service and would have clear links to those services in level 1 and may also have a key liaison role for those services in level 3.

Practitioner psychologists with dedicated time for providing services to a paediatric HIV team support the wider health/medical team in both direct and consultative ways. The following areas are those from other chronic childhood health conditions where positive outcomes have been reported with practitioner psychologists adding particular expertise and are particularly relevant in psychological care for CLWH:

- Improved adherence to treatments
- Individualised preparation for procedures
- Psychological pain management
- Early identification of any cognitive changes resulting from the condition or its treatments
- Prevention/reduction in post-traumatic stress symptoms
- Early intervention for very vulnerable families
- Support for complex decision making
- Transition of adolescents to adult services
- Well supported staff

(Mercer et al 2015, Edwards & Titman 2010, Jacobs, Titman & Edwards 2012, Salmoum-Daly et al 2012, Kings Fund 2016).

In addition to the above, the Practitioner psychologist working with a specialist paediatric HIV team would also have some expertise in communication and understanding a sensitive diagnosis and any emotional consequences, coping with multiple change or bereavements, managing family difficulties, behavioural difficulties, risk assessments and capacity to consent in adolescence etc. They can provide interventions which are focussed on individual, family, peer, group or other systems including the HIV team.

It is also the more consultative and indirect support to the team from Practitioner psychologists which can also promote better psychological care from all and enhance better outcomes, Some examples include providing knowledge on child development, behavioural change and psychosocial resilience or risk factors, developing team protocols and referral pathways, producing guidelines for early screening of developmental and psychological difficulties, as well as carrying out audit and research on aspects of care and outcomes. A practitioner psychologist would be aware of whom and how to

refer on for more specific educational, psychiatric or neuropsychological services where needed and help families navigate through engagement with these.

Service Provision

The historical provision of specialist psychology services is through a variety of different funding streams and there is wide variation in the amount of Practitioner psychology provided in different UK centres. In some larger services designated sessions from a practitioner psychologist are integrated into the physical health multidisciplinary HIV team. In other centres, psychology time for CLWH and families is available as part of a generic paediatric psychology service, child mental health service, lifespan or health psychology service. Some larger centres have some dedicated funding for HIV psychology provision for CLWH. Occasionally the remit for the practitioner psychology service also includes time and resources to provide a service for uninfected but affected children, especially over coping with bereavement or disclosure concerns. Whatever the source of funding, on-going supervision and governance for the Practitioner psychology service should in part be provided by someone with psychology experience and expertise working with children and young people and families as well as by someone with HIV knowledge.

The amount of Practitioner psychology time allocated to paediatric HIV clinics should be determined by a number of factors such as the social and health complexities and age distribution of the client group attending a particular centre. It maybe that a larger number of a secondary school aged children in the population will require more access to psychology time as this group will be managing sexual health and transmission concerns with more awareness around their diagnosis as well as more demanding learning, emotional and social needs than those CLWH at younger ages and because mental health needs tend to increase during adolescent years. The skill mix and responsibilities of other HIV team members, as well as from local voluntary sector services, and the availability of psychology within other paediatric health services or adult HIV services, will be factors in determining level of practitioner psychology input.

Although numbers of children with HIV in the UK are gradually decreasing, the psychosocial and health complexity of the cases remains high. The proportion of adolescents is increasing, and the needs of adolescents in psychosocial support are higher than for children of primary school age, especially in cases with late diagnosis of perinatal HIV infection. Amount of psychology provision will depend on numbers of children and adolescents in follow up and type of provided service. Tertiary centres providing psychology input for local clinics in addition to the workload in their centres will need to estimate numbers of children at local clinics requiring annual central review. Further, appropriate time for peer meetings and case discussions for psychologists in post should be considered, as these posts are becoming increasingly specialised and it is essential to maintain professional links with other psychologists working with perinatally infected populations. Time for teaching and linking with community services and liaison with schools should also be taken in consideration.

Whilst clear recommendations for amount of psychology provision per head of population are scarce, there are some figures developed as guidance for children living with other chronic lifelong conditions. For example, for children and young people with cystic fibrosis it recommends a practitioner psychology provision of 0.4 whole time equivalent (WTE) per 50 patients (BPS/PPN document 2010). The ageing CLWH population, the cognitive implications of early HIV on the developing brain, addressing the changing processes of adherence and disclosure within complex social and family situations suggests a minimum of 0.2 WTE per 20 patients would be required. Additional WTE may be added to meet the needs of complex patients requiring ongoing liaison with family, school and social services (see the estimates below).

Suggested estimates for psychology service provision for HIV infected children and adolescents:

For smaller clinics (20 attending children or less) 2-3 sessions of dedicated psychology time (i.e. 0.2 WTE where a session is a half day) to cover team meetings, referrals for psychology input and some liaison or consultations within and out of clinic setting are required.

However extra sessions need to be provided (dependent on amount of need)

- if there are a high proportion of the clinic with developmental , learning or mental health needs which require assessment and interventions and considerable liaison with outside education, social or community services
- if there are a high proportion of adolescents in the clinic population who are in the transition processes to adult services
- if the clinic is linked with other local clinics seeing some paediatric HIV cases but without access to dedicated psychology e.g in shared care arrangements. to provide consultation or annual psychology reviews
- where there are extra research and/or teaching demands attached to the post

Conclusions

Psychological care has been demonstrated to improve outcomes in chronic conditions and needs to be integrated within health care for children and adolescents with HIV infection.

This document suggests a model of care for all those engaged in emotional support and core aspects of care that need to be addressed. The role of Practitioner Psychologists is highlighted as providing value added and cost effective expertise within the more general system of emotional support.

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Endorsements & Acknowledgements

The standards document in 2014 was endorsed by :

- **CHIVA (Children's HIV Association)** is the UK wide organisation for professionals and community organisations providing health, psychological and social care services for children and families living with HIV. CHIVA also has a structure for actively involving and including the views of young people living with HIV .
- **PPN (Paediatric Psychology Network)**. This is a professional organisation for qualified practitioner psychologists working with children and families within paediatric health settings. The PPN is part of the Faculty for Children and Young people within the Division of Clinical Psychology at the British Psychological Society.
- **Faculty for HIV & Sexual Health (BPS)** This is a subdivision of the Division of Clinical psychology at the British Psychological Society for psychologists working within sexual health and adult HIV specialties . Members of this faculty were instrumental in developing the psychology standards for adults with HIV and we are indebted to them for supporting the need for separate guidance for children and families.

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3. Psychologists with CASCAID in South London & Maudsley NHS Trust.
4. Psychologist with HIV service at Royal Free Hospital NHS trust
5. Psychologists Oxford University Hospital Trust
6. Psychologist with Paediatric HIV service at St Georges Hospital NHS Trust
7. Psychologist with Lifespan HIV service at Newham NHS Trust
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All psychologists were members of the Paediatric HIV Psychology group and were working in posts providing services for children and families with HIV whilst writing this document. Thanks also to all other members of the **PHP** (Paediatric HIV Psychology group) and many other colleagues in other HIV services and professions who commented on and guided these standards and provided much needed support for the working group members.