Chiva

GROWING TOGETHER FOR HEALTH AND HAPPINESS



PROMOTING PSYCHOLOGICAL WELLBEING FOR CHILDREN AND YOUNG PEOPLE LIVING WITH HIV

STANDARDS FOR SERVICES

Contents

Writing Group Members 1

Scope of the Standards 1

The Paediatric HIV Context and Key Challenges Faced by Children and Young People 2

Service Context 2

Standard 1: Access to Psychological Support 4

Standard 2: Active Partnerships Between Services and Children and Young People 7

Standard 3: Identifying Developmental and Psychological Needs 9

Standard 4: Support for Knowledge, Understanding and Sharing Information about HIV 12

Standard 5: Considering a Child or Young Person's Relationship with HIV Treatment 16

Standard 6: Promoting Psychological Wellbeing During Transition Between Paediatric and Adult HIV Services 18

APPENDIX: FURTHER READING 20

Writing Group Members

Dr Kristina Fenn, Clinical Psychologist and Systemic Family Therapist, Clinical Health Psychology, Alder Hey Children's NHS Foundation Trust, Liverpool.

Dr Jeremy Oliver, Consultant Clinical Psychologist in Paediatrics, St George's Hospital, London.

Dr Francesca Meredith, Clinical Psychologist, Great Ormond Street Hospital, London.

Scope of the Standards

The standards aim to prioritise and enhance the psychological wellbeing of children and young people living with perinatally acquired HIV (0-18 years, or until transition) across the UK.

They should be read alongside the Chiva Standards of Care 2025.

The Paediatric HIV Context and Key Challenges Faced by Children and Young People

1.5 million children (0-14 years) are living with HIV globally (2022). 301 children and young people are in active follow-up in England (CHARS 2024). These children and young people face challenges connected with living with a chronic health condition.

Of the 301 children and young people, 52.8% female; 58.1% born in UK/Ireland. Most were Black African ethnicity (74.8%) and 4.2% were aged 15-19 years (late teens). This cohort of children and young people may face challenges including those related to relocation, racism, and separation from family members (for those born abroad).

There is misinformation and stigmatising attitudes about HIV in society. This increases the importance of confidentiality for children and young people and fear of unplanned sharing of diagnosis. This context of stigma increases the risk of isolation, marginalization and negative impact on emotional health due to the burden of secrecy. Children and young people may also face restricted access to support due to confidentiality fears.

Children and young people may also have family members who have HIV. Their family may face challenges connected with parent/carer health, increased exposure to loss/illness, presence of family secrets, and social isolation.

Children and young people living with HIV are at increased risk of neuro-developmental and cognitive difficulties compared to the general population. This risk is reduced by early antiretroviral treatment. Children and young people may be impacted by neurocognitive difficulties and need specialised neurocognitive assessment and support.

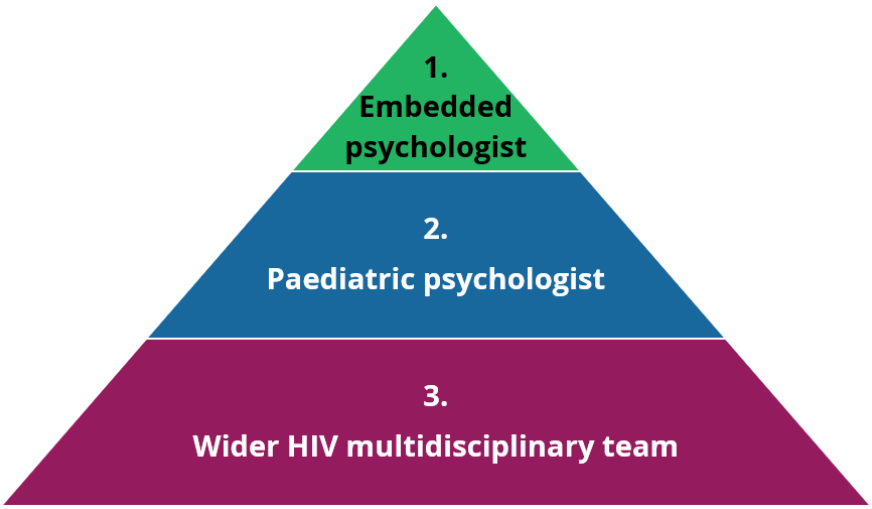
Children and young people living with HIV may also have experiences of health inequalities, comorbidities, and Adverse Childhood Experiences (ACEs). These experiences increase the risk of psychological difficulties, mental health conditions, and experiences of psychotic episodes (due to biological and social risk factors).

Service Context

All children and young people should be seen at a Lead or Specialist Interest Paediatric HIV Centre.

The multidisciplinary team (MDT) at these centres should include practitioner psychologist(s). Psychological wellbeing is also promoted by the actions of and relationships with other healthcare professionals.

The intended audience for these guidelines is therefore broad, including: All clinicians (doctors and nurses) in HIV MDTs; other healthcare professionals such as practitioner psychologists, peer support workers, dieticians, pharmacists and health advisors; commissioners; children and young people and families.



Levels of psychology involvement:

1. Embedded part of the paediatric HIV MDT
2. Paediatric psychology department that receives referrals from the HIV MDT
3. Members of the paediatric HIV MDT that support psychological wellbeing

Standard 1: Access to Psychological Support

Recommendations

- Psychological wellbeing must be routinely considered by all healthcare professionals in a children and young people's network.
- Initial access should include social and psychological review (including developmental screen) within the first two months of engagement.
- Ongoing access should include reviews as part of the annual review and at every clinic contact.
- Children and young people should be screened for symptoms of depression, anxiety, stress, self-harm risk, substance misuse, and cognitive/behavioural difficulties affecting capacity/consent.
- Children and young people should be directly asked what they want to discuss at every clinic contact. Professionals should learn about children and young people's lives and priorities outside of HIV, including who are the important people in children and young people's families and network.
- Appropriate onward referral should be made for specific needs, including Child and Adolescent Mental Health Services (CAMHS), Educational/Neuropsychology services, and specialist HIV/Paediatric Psychology. Professionals should be aware of and establish pathways with these services and follow up on the outcomes of referrals.
- Encourage and discuss peer support (including the annual Chiva camp) and refer to local HIV third sector agencies.
- If possible, facilitate opportunities for children and young people to meet the embedded psychologist, such as at HIV clinic appointments. This helps to normalise the psychologist role in the MDT and their availability, i.e. at all times and not only when there are problems. It also facilitates referrals for further psychology input and creates more opportunities for joint working within the MDT.
    - If there is not an embedded psychologist in the MDT and therefore a referral is made either to a general paediatric psychology colleague or to an external agency, e.g. CAMHS, the HIV team should offer HIV-specific consultation to those staff or agencies and signpost them to up-to-date information (e.g. Chiva Standards of Care and current Psychology Standards).

Rationale

Psychological support aims to enhance mental health and cognitive, emotional, and behavioural wellbeing. Psychological support can be integrated into care using stepped care model:

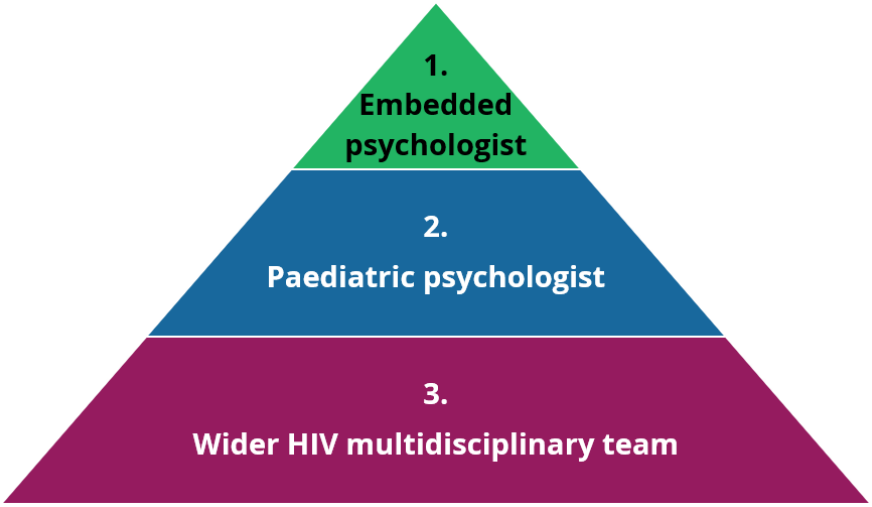
- Tier 1 (Universal): Psychological support needs of all children and young people and families met by a wide range of professionals.
- Tier 2 (Specialist): Complex needs met by appropriately trained personnel via clear referral pathways.

Consideration of psychological wellbeing should focus on living well with HIV and children and young people's priorities. Peer support is highly effective in building knowledge, confidence, self-esteem, and reducing isolation.

Implications for Commissioning and Planning

The goal for HIV centres is to have an embedded psychologist (e.g., recommendation of 0.5 whole time equivalent (WTE) per 50 children and young people due to challenges faced by children and young people).

Centres should collect evidence of need for an embedded psychologist and share with commissioners.



Levels of psychology involvement:

1. Embedded part of the MDT and involved from first entry into the service
2. Referrals for psychological support in relation to living with HIV
3. Regular reviews of psychosocial wellbeing and onward referrals

Auditable Indicators
Access to psychological services, including: • Referral routes (i.e. to embedded psychologist, paediatric psychology department, CAMHS) • Numbers of children and young people referred • Reason for referral • Outcome of referral • Waiting time

Additional Guidance

Chiva Standards of Care p.20 Standard Three: Specialist multidisciplinary paediatric HIV treatment and care: Outpatient and inpatient.

Standard 2: Active Partnerships Between Services and Children and Young People

Recommendations

- Develop positive relationships with the children and young people, parents, and carers. Ensure the young person has a key, trusted contact person in the team.
- Maintain continuity of care and communication, especially when appointments are missed or the young person is facing challenges.
- Liaise closely with voluntary sector and other services (physical/mental health).
- Maximise engagement by reducing logistical barriers and increasing flexibility.
- Ensure service users have accessible tools to feedback their views – such as the Chiva PREM - and respond to feedback from young people and their families.
- Use resources from youth-led groups (e.g., Chiva Youth Committee's "Steps to Success").
- All HIV team members should maintain up-to-date knowledge of HIV (e.g., attending Chiva conferences). Engage with youth-led symposiums to integrate their views into service delivery.

Rationale

A positive practitioner-patient relationship is highly influential on living well with HIV. Support for carers enhances involvement and positive outcomes for the children and young people. Care is enhanced when it is based on up-to-date knowledge and youth perspectives.

Implications for Commissioning and Planning

- Commission services considering location, flexible hours, and offering virtual/in-person appointments.
- Use a range of communication methods (e.g., texting).
- Ensure services are relevant, patient-centred, and responsive to the needs of children and young people and their families.

Auditable Indicators
Evidence of regular collection of children and young people's views and acting upon these, including: • Service user satisfaction questionnaires e.g. Chiva PREM www.chiva.org.uk/professionals/prems-survey/ • Focus groups • 'Patient participation' activities • Children and young people on committees and with decision-making influence

Additional Guidance

Chiva Standards of Care p.32 Standard Ten: Engagement and involvement of service users.

Standard 3: Identifying Developmental and Psychological Needs

Recommendations

All children and young people should have:

- in infancy (2-4 years) - a baseline developmental assessment to inform school support needs by identifying early difficulties in cognition, motor skills, communication, social communication, behaviour, emotion regulation, independence and learning.
- in late childhood (7-10 years) - a further baseline assessment of social, emotional and cognitive functioning to give a more detailed understanding of the child's present and predicted progress, critical to understanding any changes reported during adolescence.
- in adolescence (12-18 years) - updated screening and assessment where needed, guided by key developmental stages (e.g. puberty onset, approaching adulthood) and/or changes affecting their chronic health condition (e.g. changes in medication or clinic provision).

Rationale

- Children and adolescents with perinatally acquired HIV are vulnerable to neurodevelopmental and neurological difficulties.
- Antiretroviral therapy (ART) has led to significantly improved developmental outcomes and reduced acute and severe presentations such as progressive encephalopathy.
- Children and young people taking ART continue to experience neurodevelopmental difficulties compared to peers without HIV, in processing speed, executive functioning, and working memory, motor and language development.
- Chronic illnesses in childhood increase the likelihood of emotional and behavioural difficulties.
- For children and young people living with HIV, there can be an increased prevalence of psychiatric disorders, including psychosis, by late adolescence and early adulthood.

Implications for commissioning and planning

Psychology provision within clinics seeing children living with HIV requires adequate resources to provide developmental assessments in the early years and when older to ensure timely access to cognitive assessments and screening for social, emotional, behavioural and mood difficulties.

Formal assessment should be completed by a psychologist who is qualified to administer cognitive/psychometric assessments and interpret results. Wider MDT members can help by noticing signs of cognitive difficulties (e.g. reports from school) or emotional, behavioural and mood difficulties (e.g. conversations with parents in clinic), and giving screening questionnaires, then discussing with psychologist.

In some circumstances, children living with HIV and/or other family members may require more specialist assessments or interventions. There should be a clearly identified pathway for referral to relevant services, which may differ from one locality to another.

Auditable Indicators

The number of children and young people in the paediatric HIV service who are at following stages:

	Assessment	*Diagnosis*	*Support*
Neuro-development	On neurodevelopmental assessment pathway	Have neurodevelopmental diagnosis	Receiving support from specialist neurodevelopmental service/ organisation
Cognition and learning	Awaiting cognitive or educational psychology assessment	Have diagnosis of specific learning difficulty or intellectual disability	Receiving learning support in school, on school SEN register, or have Education and Health Care Plan
Mental health	Awaiting assessment from CAMHS, other psychological or psychiatric services	Have diagnosis/presenting with mental health condition (incl. anxiety and depressive symptoms, self-harm, psychosis, eating disorders or any other mental health difficulty	Receiving support from CAMHS, other psychological or psychiatric services

- The number of referrals the paediatric HIV service made for assessment or support in each of the above categories and whether the referral was accepted or rejected.
- The number of diagnoses above (or other) the paediatric HIV service made/confirmed.

Additional Guidance

Children living with HIV are a diverse group in relation to ethnicity and cultural experience, so developmental or psychological measures will need to be selected carefully, for meaningful assessment and interpretation.

As with all screening and assessment, clinicians will need to be mindful of false positives in scoring, the validity of cut offs, applicability of standardisation/ normative data, and the sensitivity and specificity of assessments.

A screening interview for school aged children has been developed by the Paediatric HIV psychology group. This screening interview is currently being updated and will be available on the Chiva website in early 2027. It includes a self-report quality of life measure. For younger children this screen can be used to identify those at risk of more significant difficulties and to inform at an early stage the decision to refer on for more specialist assessment.

More detailed psychological assessment should be guided by clinical judgement where significant issues with health, education, or social circumstances emerge. This could include those children living with HIV who present at clinic with unusual or difficult behaviours, significant mood changes, bereavement, significant life events or adverse childhood experiences, memory and learning difficulties, distress or anxiety over hospital visits, procedures or managing treatments.

There should be a clear referral pathway to appropriate specialist services. This may be available within the MDT or hospital setting, (e.g. paediatric psychologists), or may require onward referral to local or community specialist services for example CAMHS, educational psychology, or specialist neuropsychology services.

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

Recommendations

- Services for children living with HIV should communicate openly about HIV and its treatments from an early stage to increase children's knowledge and understanding, support management of the condition, and encourage participation in health-related conversations.
- Information, resources, and interventions aimed at increasing knowledge and understanding should be developmentally appropriate and regularly reviewed. Communication should always be in line with The People First Charter with an aim to remove language that may be stigmatising.
- Access to appropriate multi-disciplinary services (i.e., interpreters, learning disability specialists) should be available if there are difficulties with communication or comprehension when talking about HIV.
- This guidance documents the need to promote open conversation and early naming of HIV. However, psychological support should take account of individual circumstances as well as national policy around talking about and naming HIV, and support should be tailored accordingly.
- There may be many factors which influence the confidence and pace at which a child's HIV status can be discussed, both with them and with others. Factors impacting these discussions may include personal circumstances of the child and specific family experiences. Naming HIV should keep in mind wider cultural contexts and caregiver beliefs about HIV.
- More specific psychological interventions for the child, carer, family or service providers should be considered if there are concerns about the social and emotional consequences for a child or family that may arise from talking, or avoiding talking, openly about HIV.
- Practice in supporting HIV knowledge and onward sharing of diagnosis should have the child's best interest and protection at its centre, acknowledging the importance of confidentiality in relation to HIV diagnosis.
- Practitioners involved in supporting children living with HIV should have an awareness of HIV transmission including: undetectable equals untransmittable (U=U); sexual health including pre- and post- exposure prophylaxis. They should incorporate knowledge of up-to-date legislation and good practice around parental and child/young people's rights and choices. This should include an awareness of issues around capacity to consent, safeguarding, confidentiality and situations where there may be legal consequences.

- In the UK, there is no legal obligation to share a child's HIV diagnosis with other agencies, such as schools and other health and social care services. In some circumstances there can be benefits for the child if the diagnosis is shared with an appropriate member of a particular service.
- Sharing of a child's HIV status on a need-to-know basis should always be done with the knowledge of the parents/carers and the children living with HIV, if they are aware of their status, with reassurances that the service has appropriate confidentiality policies in place.

Rationale

HIV is a manageable chronic health condition. Evidence from other chronic conditions shows that communication which is based on openness between health professionals and families can help with enhancing knowledge and understanding, promoting the child's emotional adaptation to diagnosis and improving health-related coping skills. Talking to children about their HIV diagnosis is a process rather than a discreet event and will evolve as their cognitive and emotional maturity develops.

International guidance recommends that a child's emotional and cognitive maturity is taken into account when deciding what age they are told about their HIV status. Assessing the child's readiness to have their HIV named to them should begin before the age of six. It should focus on the child's capacity to understand the information and any particular needs or context considerations.

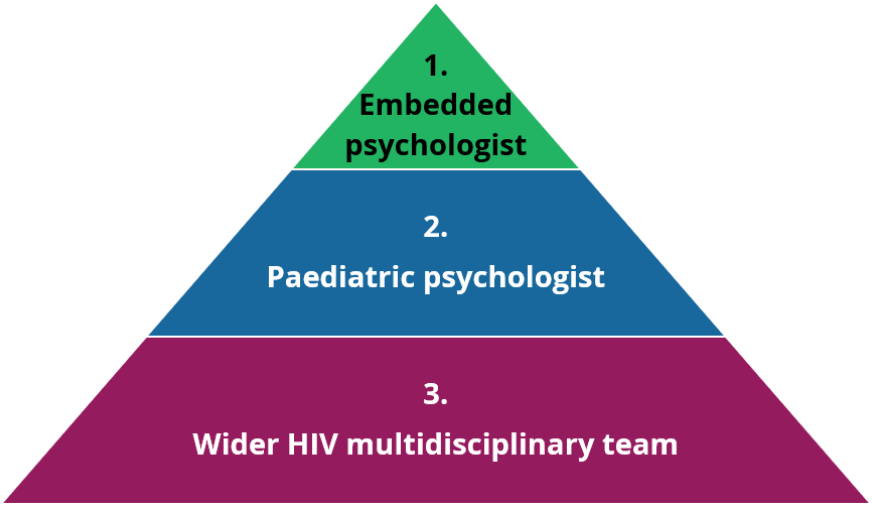
Children should have had HIV named to them in the early primary school years and certainly before the age of nine. Growing international consensus is that naming HIV when a child is younger, reduces self-stigma and empowers children and young people to adhere to their medication, make informed decisions and share their own diagnosis appropriately.

Implications for Commissioning and Planning

Psychological support for children's knowledge and adjustment to HIV may be provided by a number of different professions or services within health, social and community care and should be staggered according to need.

The following circumstances are likely to need a referral for more specialist psychology interventions:

- Where there is excessive distress from the child, carers or other family members (including other children in the family) around any discussion of HIV.
- A child has significant learning needs, communication difficulties or emotional immaturities.
- The parent has psychological, mental health or other difficulties which interfere with communicating with the child.
- There are other significant psychosocial circumstances or adverse events which interfere with the child, carer or family's wellbeing including carer changes, bereavement and loss, trauma, adjusting to life in a new country etc.



Levels of psychology involvement:

1. Embedded part of the MDT and involved from first entry into the service
2. Offer of consultation where there are obstacles or delays to discussion; accept referrals where there are specific difficulties relating to health
3. Naming and sharing of information around HIV and support pertaining to this

Auditable Indicators		
Awareness	*Obstacles/Coping*	*Support*
Children's awareness of diagnosis	Documentation of any delays or obstacles to discussions	Recording resources or information used to support conversations
Sharing of diagnosis with peers, partners and trusted others	Child's coping or emotional responses to discussions about HIV	Recording numbers requiring referral to specialist psychological services

Additional Guidance

For early conversations, use appropriate language and simplify discussions when talking to children; gradually increasing the complexity of terms used. HIV should be described as a 'virus', with discouragement of the use of ambiguous terms such as 'bug' or 'germs' due to being misleading and playing into pre-existing stigma.

Children are active learners who try to make sense of what is happening regardless of their age. Access to the internet and social media must be considered as an increasing risk to finding misinformation in their attempts to understand what is happening.

There are challenges that arise in the naming of HIV and having open conversations that require further exploration and support. Stigma-related fear, HIV-related bereavement and caregivers' experience of their own HIV diagnosis may impact readiness and willingness to have conversations with their child that may require extra psychological support.

There is advice on the Chiva website on how children living with HIV can share their diagnosis with others. It is important that apprehensions are explored with young people so that appropriate mechanisms can be put in place to support appropriate sharing of diagnosis (Grainger, 2016).

Chiva Standards of Care p.26 Standard Six: Talking to children and naming HIV.

Standard 5: Considering a Child or Young Person's Relationship with HIV Treatment

Recommendations

- Promote knowledge of each treatment's role in managing HIV and encourage increasing responsibility and autonomy over time.
- Provide planned, developmentally appropriate information and resources (e.g. from Chiva). Have resources readily available in the clinic.
- Seek to understand the pressures children and young people are facing; their priorities; their available resources (e.g. financial, transport); and any restrictions to these from stigma (e.g. not wanting others to see medication).
- Acknowledge and integrate social, family, and religious beliefs to tailor support effectively.
- Maintain ongoing, curious, and open dialogue with the young person and family about different beliefs and attitudes.
- Engage family/carers and potentially identify a mentor (peer or external). Work in partnership with charities/support networks.
- Identify and address varied, individual reasons for not engaging with treatment. Support - do not blame - the children and young people.
- Seek to understand and document barriers. Interventions may include medication changes, practical support, social/peer support, or psychological interventions. Assess capacity for decision-making. Maintain ongoing contact even if treatment is stopped.
- Facilitate access to evidence-based, tailored interventions delivered by qualified professionals.

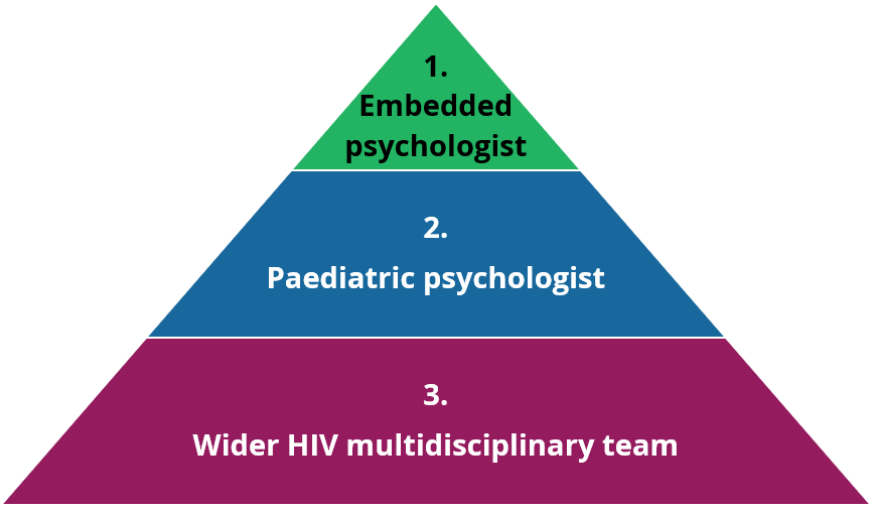
Rationale

Children and young people's relationship with treatment is impacted by the many and varied aspects of their lives. Active support from others can help integrate treatment into daily life.

Implications for Commissioning and Planning

- Ensure referral accessibility for specialist psychological support (e.g., CBT, Motivational Interviewing, Narrative Therapy). Refer for support with mental health difficulties (e.g. to CAMHS).
- Integrate psychological expertise into the clinic setting to provide comprehensive, preventative, and training support.

- Embedded Psychologist: Provide joint working/consultation in clinics, deliver training to the MDT, facilitate group sessions/peer support, and provide preventative input.



Levels of psychology involvement:

1. Embedded part of the MDT
2. Referrals for specialist psychological support
3. Use the above recommendations to support children and young people's relationship with treatment

Auditable Indicators
• Proportion of children and young people on suppressive ART. • Proportion of children and young people offered additional support, e.g. peer support, psychological support, third sector support. • Documentation of barriers to treatment and ways these are addressed.

Additional Guidance

Chiva Standards of Care p.25: Standard Five: Adherence Support.

Standard 6: Promoting Psychological Wellbeing During Transition Between Paediatric and Adult HIV Services

Recommendations

- Each child and young person should be involved in creating an early, collaborative transition plan with their HIV MDT.
- Plans should promote HIV knowledge, sexual health understanding, treatment participation and increasing independence
- Young people should receive developmentally appropriate sexual health support. Care should promote positive sexual wellbeing, not just prevention of transmission.
- Transition planning should consider the child or young person's broader priorities and life goals, e.g. education, employment, independence, not solely health outcomes.

Rationale

Transition should be a gradual, structured process preparing young people for age-appropriate services. It is ongoing and addresses practical, medical, social and emotional needs - not simply transfer between clinics.

National guidance recommends structured transition processes. Poorly managed transition is linked to worse clinical outcomes, including reduced attendance, poorer adherence and poorer mental health.

Adolescence is a vulnerable period for mental health, particularly for those living with lifelong health conditions. Young people living with HIV face additional pressures including stigma.

Young people often report mixed feelings about transition to adult services, with considerations including attachment to paediatric teams and confidentiality concerns.

Implications for Commissioning and Planning

Multidisciplinary teams should include practitioners skilled in adolescent psychological development to support autonomy and self-management. Services should have a documented transition model integrating psychological and physical healthcare.

Auditable Indicators
• Availability of transition information for children and young people and carers. • Availability of sexual health education resources. • Proportion of children and young people with documented transition plans. • Clinical outcomes following transition, such as CD4 counts and number of hospital admissions. • Numbers referred for extra psychological support both before and after transfer and reason and outcome of referral.

Additional Guidance

- BASHH sexual health guidelines: https://www.bashh.org/resources/guidelines/
- Chiva Standards of Care p.29 Standard Eight: Transition to adolescent, youth, and adult HIV specialist services.
- Chiva Guideline on Transition for Adolescents Living with HIV www.chiva.org.uk/guidelines

APPENDIX: FURTHER READING

Chiva (2025) *Standards of Care for Infants, Children, and Young People with HIV and infants born to mothers/birthing parents with HIV*. www.chiva.org.uk/guidelines

The Paediatric HIV Context and Key Challenges Faced by Children and Young People

Arenas-Pinto, A. et al. (2022) *Learning and memory function in young people with and without perinatal HIV in England*. *Adolescents and Adults Living with Perinatal HIV (AALPHI).* PloS ONE.

Benki-Nugent, S. et al. (2023) *Early Antiretroviral Therapy Reduces Severity but Does Not Eliminate Neurodevelopmental Compromise in Children With HIV*. JAIDS Journal of Acquired Immune Deficiency Syndromes.

Bernays, S. et al. (2015) *What am I "living" with? Growing up with HIV in Uganda and Zimbabwe*. Sociology of Health & Illness.

Blokhuis, C. et al. (2016) *Neurodevelopmental delay in pediatric HIV/AIDs: current perspectives.* Neurobehavioral HIV Medicine.

British Psychological Society (BPS)/ British HIV Association (BHIVA) (2025) *Standards for Psychological Support for Adults Living with HIV.* BHIVA.

Carter, B. and McGoldrick, M. (2015) *The Expanding Family Life Cycle: Individual, Family and Social Perspectives*. Pearson.

Children's HIV and AIDS Reporting System (CHARS) (2024) *Annual Report 2022-23*. Accessed at: https://www.ucl.ac.uk/chars/sites/chars/files/chars_report_2024.pdf

Dahmani, S. Rakhmanina, N. Jiang, X. (2024) *Cognitive impairment in children and adolescents living with perinatal HIV disease in the ART era: a meta-analysis*. eClinicalMedicine.

Distelberg, B. et al. (2014) *Evaluation of a family systems intervention for managing pediatric chronic illness: Mastering Each New Direction (MEND).* Family Process.

Dorrell, J. and Katz, J. (2013) *"I knew I had something bad because no-one spoke about it" – disclosure discovery: Experiences of young people with perinatally acquired HIV in the UK*. Vulnerable Children and Youth Studies.

Edwards, M. and Titman, P. (2010) *Promoting Psychological Well-Being in Children with Acute and Chronic Illness*. Jessica Kingsley Publishers.

Gibbs, C. et al. (2020) *'I don't even know how to start that kind of conversation': HIV communication between mothers and adolescents with perinatally acquired HIV*. Journal of Health Psychology

Horton, R. H. et al. (2025) *Neuropsychiatric outcomes in children and adolescents with perinatally acquired HIV: A systematic review and meta-analysis.* JAIDS Journal of Acquired Immune Deficiency Syndromes.

Jantarabenjakul, W. et al. (2019) *DOET study. Low risk of neurodevelopmental impairment among perinatally acquired HIV-infected preschool children who received early antiretroviral treatment in Thailand*. Journal of the International AIDS Society.

Judd, A. et al. (2016) *Cognitive function in young persons with and without perinatal HIV in the AALPHI cohort in England: Role of non–HIV-related factors.* Clinical Infectious Diseases.

Kazak, A.E. et al. (2024) *Pediatric psychosocial preventative health model: Achieving equitable psychosocial care for children and families*. Families, Systems, & Health.

Laughton, B. et al. (2012) *Early antiretroviral therapy improves neurodevelopmental outcomes in infants*. AIDS.

Laughton, B. et al. (2018) *Five year neurodevelopment outcomes of perinatally HIV-infected children on early limited or deferred continuous antiretroviral therapy.* Journal of the International AIDS Society.

Le Prevost, M. et al. (2018) *Anxiety and depression symptoms in young people with perinatally acquired HIV and HIV affected young people in England*. AIDS Care.

Malee, K.M. et al and Pediatric HIV/AIDS Cohort Study Team. (2011) *Mental health functioning among children and adolescents with perinatal HIV infection and perinatal HIV exposure*. AIDS Care.

Malee, K.M. et al. (2017) *Impact of perinatally acquired HIV disease upon longitudinal changes in memory and executive functioning*. JAIDS Journal of Acquired Immune Deficiency Syndromes.

Mallik, I. et al. (2022) *Psychotic disorders in young adults with perinatally acquired HIV: A UK case series*. Psychological Medicine.

Mellins, C. and Malee, K. (2013) *Understanding the mental health of youth living with perinatal HIV infection: Lessons learned and current challenges*. Journal of the International Aids Society.

Nicolucci, A. et al. (2013) *Diabetes Attitudes, Wishes and Needs second study (DAWN2™): Cross-national benchmarking of diabetes-related psychosocial outcomes for people with diabetes*. Diabetic Medicine.

Robbins, R.N. et al. (2020) *Longitudinal trajectories of neurocognitive test performance among individuals with perinatal HIV-infection and -exposure: Adolescence through young adulthood*. AIDS Care.

Royal College of Paediatrics and Child Health (2018) *Facing the Future: standards for children with ongoing health needs.* RCPCH.

World Health Organization (WHO) (2023) *HIV Data and Statistics*. Accessed at: Global HIV Programme (who.int)

Standard 1: Access to Psychological Support

Bhana, A. et al. (2021) *Interventions to address the mental health of adolescents and young adults living with or affected by HIV: state of the evidence*. Journal of the International Aids Society.

British Psychological Society (BPS)/ British HIV Association (BHIVA) (2025) *Standards for Psychological Support for Adults Living with HIV.* BHIVA.

British Psychological Society (BPS) (2025) *Standards for Paediatric Psychology Services.* BPS.

Chiva. (2022) Wellbeing Toolkit. Resource for health professionals working with children and young people living with HIV. https://www.chiva.org.uk/wp-content/uploads/2022/06/Wellbeing-Toolkit-website-copy-.pdf

Laurenzi, C. et al. (2020) *Preventing mental health conditions in adolescents living with HIV: an urgent need for evidence*. Journal of the International AIDS Society.

Malee, K.M. et al and Pediatric HIV/AIDS Cohort Study Team (2011) *Mental health functioning among children and adolescents with perinatal HIV infection and perinatal HIV exposure*. AIDS Care.

Medin, G. et al. (2015). *Disease disclosure, treatment adherence, and behavioural profile in a cohort of vertically acquired HIV-infected adolescents. NeuroCoRISpeS study.* AIDS Care.

NICE Guidelines (2015) *Depression in children and young people: Identification and management.* [NG134].

Persson, A., et al. (2014) *Caring for 'underground' kids: qualitative interviews with clinicians about key issues for young people growing up with perinatally acquired HIV in Australia.* International Journal of Adolescence and Youth.

Robinson, A. et al. (2025) *Examining the relationship between HIV-related stigma and the health and wellbeing of children and adolescents living with HIV: A systematic review.* AIDS and Behavior.

Royal College of Paediatrics and Child Health (2018) *Facing the Future: standards for children with ongoing health needs.* RCPCH.

Saberi, P. et al. (2020) *Use of technology for delivery of mental health and substance use services to youth living with HIV: a mixed-methods perspective.* AIDS Care.

Vreeman, R.C. McCov, B.M. Lee, S. (2017) *Mental health challenges among adolescents living with HIV*. Journal of International AIDS Society.

Standard 2: Active Partnerships Between Services and Children and Young People

Distelberg, B. et al. (2014) *Evaluation of a family systems intervention for managing pediatric chronic illness: Mastering Each New Direction (MEND).* Family Process.

Edwards, M. and Titman, P. (2010) *Promoting Psychological Well-Being in Children with Acute and Chronic Illness*. Jessica Kingsley Publishers.

Goodrum, N.M. et al. (2022). *Parenting stress predicts longitudinal change in parental involvement among mothers living with HIV*. Journal of Family Psychology.

Kazak, A.E. et al. (2024) *Pediatric psychosocial preventative health model: Achieving equitable psychosocial care for children and families*. Families, Systems, & Health.

Standard 3: Identifying Developmental and Psychological Needs

Blokhuis, C. et al. (2016) *Neurodevelopmental delay in pediatric HIV/AIDs: current perspectives.* Neurobehavioral HIV Medicine.

Brady, A. Deighton, J. and Stansfeld, S. (2021) *Chronic illness in childhood and early adolescence: A longitudinal exploration of co-occurring mental illness*. Developmental Psychopathology.

Comley-White, N. Ntsiea. and V. Potterton, J. (2024). *Physical functioning in adolescents with perinatal HIV*. AIDS care.

Dahmani, S. Rakhmanina, N. and Jiang, X. (2024). *Cognitive impairment in children and adolescents living with perinatal HIV disease in the ART era: a meta-analysis*. EClinicalMedicine.

Freeman, A. (2016) *The role of neuropsychology in UK paediatric HIV care: Relevance to clinical practice and research*. Child Neuropsychology.

Horton, R. H. et al. (2025) *Neuropsychiatric outcomes in children and adolescents with perinatally acquired HIV: A systematic review and meta-analysis.* JAIDS Journal of Acquired Immune Deficiency Syndromes.

Judd, A. et al. (2016) *Cognitive function in young persons with and without perinatal HIV in the AALPHI cohort in England: Role of non–HIV-related factors.* Clinical Infectious Diseases.

Le Prevost, M. et al. (2018) *Adolescents and Adults Living with Perinatal HIV (AALPHI) Steering Committee. Anxiety and depression symptoms in young people with perinatally acquired HIV and HIV affected young people in England*. AIDS Care.

Mabrouk, A. Ssewanyana, D. and Abubakar, A. (2023). *Neurodevelopmental and mental health outcomes of HIV in school-age children*. In A. Abubakar. et al. *Recent advances in the neurological and neurodevelopmental impact of HIV.* (pp. 164-179). Mac Keith Press.

Malee, K.M. et al. (2017) *Impact of perinatally acquired HIV disease upon longitudinal changes in memory and executive functioning*. JAIDS Journal of Acquired Immune Deficiency Syndromes.

Mallik, I. et al. (2022). *Psychotic disorders in young adults with perinatally acquired HIV: A UK case series*. Psychological Medicine.

Mudawarima, L.R. Mohamed, A. and Donald, K.A. (2023). *The effect of HIV infection on neurodevelopment, from birth to 3 years*. In A. Abubakar. et al. *Recent advances in the neurological and neurodevelopmental impact of HIV.* (pp. 138-163). Mac Keith Press.

NICE Guidelines (2015) *Depression in children and young people: Identification and management.* [NG134].

Phillips, N. et al. (2022) *Youth perinatal HIV-associated neurocognitive disorders: association with functional impairment*. AIDS Care.

SSewanyana, D. Nyongesa, M.K. and Abubajar, A. (2023). *Neurobehavioural manifestations of HIV in adolescence*. In A. Abubakar. et al. *Recent advances in the neurological and neurodevelopmental impact of HIV.* (pp. 180-208). Mac Keith Press.

Yu, X. et al. (2025). *Assessing Glymphatic Function, Global Brain Activity, and Cognitive Performance in Adolescents Living With Perinatal HIV Exposure*. European Journal of Neuroscience.

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

Britto C. et al. (2016). *Prevalence and correlates of HIV disclosure amongst children and adolescents in low- and middle-income countries: A Systematic Review*. J Dev Behav Pediatr.

Cantrell, K. et al. (2013). *Pediatric HIV Disclosure: A process-oriented framework*. AIDS Education and Prevention.

Chiva. (2014). *Open and Honest Practice. Chiva Statement.* Available at: https://www.chiva.org.uk/professionals/open-and-honest-practice/

Conway, M. (2022) *HIV in Schools: Good practice Guide to Supporting Children Infected or Affected by HIV*. Chiva and National Children's Bureau.

Doat, A-R, Negarandeh, R. and Hasanpour, M. (2019). *Disclosure of HIV status to children in Sub-Suharan Africa: A Systematic Review*. Medicina.

Evangeli, M. Kagee A. (2016). *A model of paediatric HIV disclosure decision-making*. Psychology, Health & Medicine.

Evangeli, M. (2018) *The Adolescent HIV Communication Belief Scale: Preliminary Reliability and Validity Journal of Chid and Family Studies*. Journal of Child and Family Studies.

Evangeli, M. et al. (2020). *A randomised feasibility trial of an intervention to support sharing of HIV status for 18–25-year olds living with perinatally acquired HIV compared with standard care: HIV Empowering Adults' Decisions to Share—UK/Uganda Project (HEADS-UP)*. Pilot and Feasibility Studies.

Grainger, C. (2016). *Understanding disclosure behaviours in HIV-positive young people*. Journal of Infection Prevention.

People First Charter (2022), https://peoplefirstcharter.org/

Punpanich, W. et al. (2014). *Factors associated with caretaker's readiness for disclosure of HIV diagnosis to HIV-infected children in Bangkok, Thailand*. International Journal of STDS & AIDS.

Ranmal, R. Proctor, M. and Scott, J.T. (2012) *Interventions for improving communication with children and adolescents about their cancer*. The Cochrane Collaboration.

Rowson K. 2017. *Naming HIV to Children: it's time to talk*. HIV Nursing.

Rushforth, H. (1999) *Practitioner review: Communicating with hospitalised children: Review and application of research pertaining to children's understanding of health and illness*. Journal of Child Psychology and Psychiatry.

Royal College of Paediatrics and Child Health (2018) *Facing the Future: standards for children with ongoing health needs.* RCPCH.

Sopena, S. et al. (2010) *Coping and psychological adjustment in adolescents with vertically acquired HIV*. AIDS Care.

Vreeman, R.C. et al. (2010). *The perceived impact of disclosure of pediatric HIV status on Pediatric Antiretroviral Therapy adherence, child well-being, and social relationships in a resource-limited setting*. AIDS Patient Care and STDs.

Vreeman, R.C. et al. (2013). *Disclosure of HIV status to children in resource-limited settings: a systematic review*. Journal of the International AIDS Society.

Vreeman, R.C. et al. (2014). *A cross-sectional study of disclosure of HIV status to children and adolescents in western Kenya*. PLOS One.

Warburton, K. et al. (2022) *Talking to children about their HIV diagnosis: a discussion rooted in different global perspectives*. British Journal of Nursing.

Weiner, L. et al. (2007) *Disclosure of an HIV diagnosis to children: History, Current research and future directions*. Journal of Developmental and Behavioral Pediatrics.

World Health Organization (WHO) (2025) *Supporting disclosure among children and adolescents living with HIV: interventions, emerging considerations, key gaps and key actions*. https://www.who.int/publications/i/item/9789240111196

World Health Organization (WHO) (2011) *Guideline on HIV Disclosure counselling for children up to 12 years of age*. https://www.who.int/publications/i/item/9789241502863

Standard 5: Considering a Child or Young Person's Relationship with HIV Treatment

Carcone, A. I. et al. (2020). *Provider behaviors that predict motivational statements in adolescents and young adults with HIV: a study of clinical communication using the Motivational Interviewing framework*. AIDS care.

Christodoulou, J. et al. (2020). *Crystal clear with active visualization: understanding medication adherence among youth living with HIV*. AIDS and Behavior.

Department of Health. (2005). *Mental Capacity Act.* London: HMSO https://www.legislation.gov.uk/ukpga/2005/9/contents

Desai, N. (2019). *The role of motivational interviewing in children and adolescents in pediatric care*. Pediatric annals.

Foster, C. (2025) *Supporting adherence in adolescents and young adults living with HIV.* CHIVA.

Judd, A. et al. (2020) *Factors associated with nonadherence to antiretroviral therapy among young people living with perinatally acquired HIV in England*. The Journal of the Association of Nurses in AIDS Care.

Miah, J. and Melvin, D. (2011) *Me, My Health & My Medicines: An Interactive Workbook for Primary School Aged Children in Medical Settings.* Children with AIDS Charity (CWAC).

Naar, S. et al. (2020) *Comparative effectiveness of community-based vs clinic-based healthy choices motivational intervention to improve health behaviors among youth living with HIV: a randomized clinical trial*. JAMA network open.

Naar, S. et al. (2021) *Tailored motivational interviewing (TMI): Translating basic science in skills acquisition into a behavioral intervention to improve community health worker motivational interviewing competence for youth living with HIV*. Health Psychology.

NICE Guidelines (2009) *Developed by the National Collaborating Centre for Primary Care, Medicines Adherence: Involving Patients in Decisions About Prescribed Medicines and Supporting Adherence*. [CG76].

NICE Guidelines (2015) *Medicines optimisation: the safe and effective use of medicines to enable the best possible outcomes.* [NG5]

Nyamaruze, P. Govender, K. and Cowden, R.G. (2021) *Self-esteem and antiretroviral therapy adherence among young people living with HIV: An exploratory serial mediation analysis*. South African Journal of Science.

Okonji, E.F. et al. (2020). *Psychosocial support interventions for improved adherence and retention in ART care for young people living with HIV. (10–24 years): a scoping review.* BMC Public Health.

Piran, C.M.G. et al. (2025) *Social determinants of adherence to antiretroviral therapy among adolescents and young people living with HIV: A scoping review.* Revista da Escola de Enfermagem da USP.

Rollnick, S. (2005) Presentation: *Motivational interviewing and adherence support; from boom, boom to pita-pata, pita-pata*. Paediatric Aids Treatment for Africa Conference. Cape Town, South Africa.

World Health Organization (2003) *Adherence to long-term therapies: Evidence for action*.

Standard 6: Promoting Psychological Wellbeing During Transition Between Paediatric and Adult HIV Services

Campbell, T. et al. (2010) '*I look forward. I feel insecure but I am ok with it'. The experience of young HIV+ people attending transition preparation events: A qualitative investigation*. AIDS Care – Psychological and Socio-Medical Aspects of AIDS/HIV.

Chiva (2026) *Guidance on Providing Sexual and Reproductive Healthcare for Young People Living with HIV*.

Chiva (2026) *Guidance on Transition for Adolescents Living with HIV*.

Department of Health (2004) *National Service Framework for Children, Young People and Maternity Services*.

Department of Health (2008) *Transition Moving on Well: A Good Practice Guide*.

Department of Health (2011) *You're Welcome – Quality criteria for young people friendly health services*.

Frize, G. et al. (2011) *Psychology service evaluation in a clinic for young people (over 16 years) living with HIV and transitioning to adult care*. 17th annual British HIV Association Conference, Bournemouth, Abstract P168, British HIV Association. HIV Medicine.

Hamblin, E. (2011) *Just Normal Young People: Supporting Young People Living with HIV in Their Transition to Adulthood*. National Children's Bureau.

Hogwood, J. Campbell, T. and Butler, S. (2012) *I wish I could tell you but I can't: Adolescents with perinatally acquired HIV and their dilemmas around self-disclosure*. Clinical Child Psychology and Psychiatry.

Le Prevost, M. et al. (2018) *Anxiety and depression symptoms in young people with perinatally acquired HIV and HIV affected young people in England*. AIDS Care.

Office for National Statistics (2017). *Live births to women aged under-18 in EU-28 countries: 2005, 2014 & 2015*.

Machado, D.M. et al. (2016). *Adolescents growing with HIV/AIDS: experiences of the transition from pediatrics to adult care*. Brazilian Journal of Infectious Diseases.

Moss, R. Farrant, B. and Byrnes, C.A. (2021) *Transitioning from paediatric to adult services with cystic fibrosis or bronchiectasis: what is the impact on engagement and health outcomes?* Journal of Paediatrics and Child Health.

Newman, C.E. et al. (2016) *"Just take your medicine and everything will be fine": Responsibilisation narratives in accounts of transitioning young people with HIV into adult care services in Australia*. AIDS care.

NICE Guidelines (2015) *Depression in children and young people: Identification and management.* [NG134].

NICE Guidelines (2016) *Transition from children's to adult's services for young people using health and social care services* [NG43].

Ritchwood, T.D. et al. (2020). *Healthcare retention and clinical outcomes among adolescents living with HIV after transition from paediatric to adult care: A systematic review.* BMC Public Health.

Scholz, B. et al. (2019). Transitioning from adolescent to adult mental health services: an integrative literature review. Issues in Mental Health Nursing.

Straub, D.M. and Tanner, A.E. (2018). *Health-care transition from adolescent to adult services for young people with HIV*. The Lancet Child & Adolescent Health.

Valenzuela, J.M. et al. (2011). *Transition to adult services among behaviorally infected adolescents with HIV - a qualitative study*. Journal of Pediatric Psychology.



GROWING TOGETHER FOR
HEALTH AND HAPPINESS

Chiva
Orchard Street Business Centre
13 Orchard Street
Bristol
BS1 5EH

©2026 Chiva
Charity no. 1122356
Company no. 06337017

www.chiva.org.uk