

# Just Normal Young People

Supporting young people living  
with HIV in their transition to adulthood

A report from the Children and Young People HIV Network

Emily Hamblin



**HiV**  
Children and  
Young People  
HIV Network



[Blank page]

# Just Normal Young People

## Supporting young people living with HIV in their transition to adulthood

*A report from the Children and Young People HIV Network*

*Emily Hamblin*



The Children and Young People HIV Network is a national network that brings together a wide range of organisations and practitioners concerned with children and young people who are living with and/or affected by HIV and AIDS, from conception to adulthood.

The aims of the Network are to provide an effective voice for this cohort through participation work, to challenge the stigma and discrimination associated with HIV and to build child-centred policy and practice recommendations.

The Network meets its aims through national and local policy influencing; development and dissemination of good practice and information; and running training and other events. It acts as a hub for practitioners to share and obtain information, resources and contacts. It also does some advocacy and media work.

Find out more about the Network and access resources at [www.ncb.org.uk/hiv](http://www.ncb.org.uk/hiv)

NCB's vision is a society in which all children and young people are valued and their rights are respected.

Published by the National Children's Bureau. Registered Charity Number 258825.  
8 Wakley Street, London EC1V 7QE. Tel: 020 7843 6000

© NCB, November 2011

# Contents

<b>Acknowledgements</b> .....	<b>5</b>
<b>Executive summary</b> .....	<b>6</b>
<b>Introduction</b> .....	<b>8</b>
Terms and definitions.....	8
Project methodology.....	10
<b>An overview of young people living with HIV</b> .....	<b>12</b>
Children and young people accessing HIV care in the UK and Ireland.....	12
Individuals aged 16–24 accessing HIV care in the UK: 2010.....	12
New diagnoses amongst individuals aged 16–24 in the UK: 2010.....	12
The health and well-being of young people living with HIV in the UK.....	13
A general picture.....	13
Adherence to antiretroviral therapy.....	13
Sexual and reproductive health and sexual behaviour.....	14
<b>Policy and practice guidance on transition</b> .....	<b>15</b>
General guidance on transition.....	15
Guidance on transition and HIV.....	16
<b>The changing concerns of young people living with HIV</b> .....	<b>17</b>
The adult lives young people want.....	17
Young people.....	17
Young adults.....	19
<b>Support available to young people during transition</b> .....	<b>21</b>
Health services working with young people.....	21
Voluntary sector services working with young people.....	23
Statutory social care services working with young people.....	24
Other services working with young people.....	25
Young people's role in supporting each other.....	25
Sources of support described by young people.....	27
<b>Experiences and challenges</b> .....	<b>29</b>
Key messages.....	29
'Just normal young people'.....	29
Stigma.....	29
Poor adherence and loss to follow-up in healthcare.....	30
Funding and workload.....	30
Meeting the full range of diverse needs.....	30
Talking and learning about HIV.....	30
Disclosure.....	30
Learning about HIV and treatment.....	32
Openness about HIV.....	35
Discussing sex and relationships.....	36
Access to appropriate services for young people.....	39
Statutory social care.....	39
The geographical distribution of services.....	40

Perceptions of transition and adult services .....	42
Awareness of changes.....	42
Adult environments .....	44
Being amongst older adults.....	45
Developing independence and self-management skills .....	46
Getting the balance right .....	46
Clinic appointments .....	51
Managing medication .....	52
Disclosing HIV to friends and partners .....	54
Transition and the family .....	56
Health and well-being .....	57
Professional approaches .....	60
Collaboration .....	60
Awareness and attitudes .....	61
Capacity and skills.....	63
<b>Case studies of interventions designed to address specified needs .....</b>	<b>66</b>
<b>Conclusions.....</b>	<b>71</b>
Recommendations for transition practice and service development .....	72
Policy recommendations .....	73
<b>References .....</b>	<b>75</b>

## Acknowledgements

We would like to thank all the young people, practitioners, parents and carers who shared their experiences during this piece of work. Our particular gratitude goes to the young people and young adults, who spoke openly and honestly about their experiences, which have informed this work.

Acknowledgement is also given to the following people and organisations which supported the development of this publication in various ways.

Jill Hellings, Hester Cox and Barnardo's; Catherine Dufton and Blue Sky Trust; Nimisha Tanna and Body & Soul; Zetta Thomelin of Children with AIDS Charity (CWAC); Magda Conway, the CHIVA Youth Committee and the Children's HIV Association of the UK and Ireland (CHIVA); 'Chris' the HIV Clinical Nurse Specialist; Michelle Overton and Faith in People with HIV; Sally Scott of Heart of England NHS Foundation Trust; Jo Dodge of Imperial College Healthcare NHS Trust; Dr Caroline Foster of Imperial College Healthcare NHS Trust; Diane Melvin of Imperial College Healthcare NHS Trust; Chaz Ram and Leicestershire AIDS Support Services; Ailsa Pickering of Newcastle upon Tyne Hospitals NHS Foundation Trust; Dr Tomás Campbell of Newham Psychological Services (NHS); Dr Angela Robinson of NHS Camden; Zoe Cricks of NHS Luton; Katie Rowson of Pennine Acute Hospital NHS Trust; Vicki Morris of Positive Parenting and Children (PPC); Angelina Namiba, Stella Gwimbi, Positively UK's Peer Youth Case Worker and Positively UK; Karen Johnson of Sheffield City Council; Dr Karen Rogstad of Sheffield Teaching Hospitals NHS Foundation Trust; Zoe Davies of Shield South Yorkshire; Yvette Weston and Terrence Higgins Trust; Wazir Ausalut of University Hospitals of Leicester NHS Trust; Amanda Ely (NCB Associate) and Sheryl Burton, Linda Toocaram, Steve Howell and Zoë Renton (NCB).

We are also grateful to those who have facilitated opportunities to share the findings from this project, and who continue to do so.

This project is funded by a grant from the Department of Health.

## Executive summary

*HIV is not me, HIV is a part of me. I'm not a part of it. [...] I just think sometimes in like services [...] they just need to realise that HIV is a part of you but that's not the only thing that might bother us [...] I know I've got HIV. Cool. But [...] we're young still! We're just normal young people.*

The UK has an ageing cohort of children living with HIV, and their transition from childhood to adulthood is a current issue for services. This report from the Children and Young People HIV Network explores the experiences of young people living with HIV as they take steps towards greater independence and access services differently, as well as the perspectives of practitioners, parents and carers guiding young people through this process. It provides an overview of current transition practice in children's and adult health, social care and voluntary sector services in England.

An initial literature review examined current thinking on transition for young people with HIV and other long-term conditions. The Network then conducted focus groups with 123 practitioners; group consultations and one-to-one interviews with HIV positive young people aged 13–28; and a small-scale consultation event with four parents and carers.

Key findings include:

- There is great diversity of experience amongst young people, parents/carers, and practitioners severally; health, social care and voluntary sector services each play important roles in transition
- Young people want to be treated as 'normal', recognised as whole people with the same interests and concerns as their peers, and need support that enables them to lead ordinary lives in which HIV is not a focal point
- Stigma underpins or complicates many of the challenges identified for young people in making a smooth transition into adulthood
- Some complex physical, mental, emotional and/or social challenges and needs influence the transition experiences of many young people
- Transition is a critical time for adherence to HIV treatment and engagement with healthcare
- Some young people, including young adults, experience barriers to accessing age-appropriate support that meets their needs; the practitioners consulted expressed a strong commitment to supporting this age group but faced difficulties, often relating to resources and technical capacity.



This report recommends that:

- Young people living with HIV have access to a range of local, national and virtual services that are age-appropriate and responsive to their range of needs
- Services take a holistic approach to supporting young people and promote independence and self-management skills, including helping young people to access non-specialist services
- Practitioners and parents/carers work together to ascertain and respond to young people's needs, and address needs in the wider family that may impact on transition
- Transition pathways are clear, with named individuals taking the lead within services, and strong communication within and across services
- The wealth of experience and expertise within the sector are used to address skills gaps and share tools amongst practitioners working on transition, and promote HIV awareness in the wider workforce.

The report's policy recommendations aim to:

- Ensure that the needs of young people living with HIV and their families are addressed in the new landscape of health and social care services currently emerging, and promoting successful coordination of services
- Advance understanding of HIV within the broad health and social care workforce, and improve education of young people about HIV as part of personal, social, health and economic (PSHE) education
- Ensure that voluntary organisations are able to continue working effectively to support young people living with HIV within the current economic climate.

## Introduction

Thanks to advances in HIV treatment, children who were born with HIV are now living into adulthood. Services working with children and adults living with HIV have needed to adapt to support this cohort of young adults with lifelong HIV infection. Likewise, services need to meet the needs of young people who are acquiring HIV in other ways.

This report considers how young people living with HIV make the transition from childhood to adulthood and, in particular, changes in services and support for young people that occur during this time. The report presents experiences described by young people living with HIV, practitioners, and parents and carers. It considers the whole young person and the full range of changes happening to an individual during adolescence and young adulthood, as well as all the services and practitioners involved at this time.

The report aims to provide a broad picture of current practice around transition, and people's experiences of this; explore and raise awareness of the challenges associated with transition; share ways in which young people and those who help guide them into adulthood address these challenges; and recommend factors to be considered when providing and developing support for young people with HIV.

This project covers England. However, the consultation process included participation from some practitioners working in Wales, and one young person living in another UK country. It is hoped that this work will have relevance for, and be useful to, practitioners and services across the UK.

## Terms and definitions

### *Transition*

The Department of Health uses a definition of transition by Blum and others (1993):

*A purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents and young adults with chronic and medical conditions as they move from child-centred to adult-oriented health care systems.*

This report also applies the term 'transition' to services beyond healthcare.

### ***Other terms***

AIDS – acquired immune deficiency syndrome.

Adherence – sticking to an HIV treatment regimen. Optimal adherence is generally defined as taking at least 95 per cent of doses correctly.

Affected by HIV (with reference to a young person) – living in a family in which one or more members are infected with HIV, having been bereaved by HIV, or in an intimate relationship with an HIV positive person.

Antiretroviral therapy (ART) – the general name given to the combinations of antiretroviral drugs (ARVs) prescribed to HIV positive people.

CD4 count – CD4 cells are white blood cells that play an important role in the immune system and that get destroyed by HIV. A high CD4 count indicates a healthy immune system.

Children – people under 18 years of age.

GUM – genitourinary medicine.

HIV – human immunodeficiency virus.

HAART – highly active antiretroviral therapy, which typically comprises three or four drugs.

Horizontal infection or transmission – HIV infection or transmission through any route other than from mother to child: in the UK, this is usually through unprotected sex.

Living with HIV (with reference to a young person) – infected with HIV.

Support worker – young people tended to use ‘support worker’ in the context of voluntary sector services. Given that the practitioners to whom they are referring may have a number of different roles and job titles, the term ‘support worker’ is used in this report to mean an employee of a voluntary organisation who does direct work with individual young people.

Vertical infection or transmission – HIV being transmitted from a mother to her child *in utero*, during birth or via breastfeeding.

Viral load – the amount of HIV in the blood. When a person’s viral load is ‘undetectable’, it is so low that it cannot be reliably detected in a test, though s/he is still HIV positive. An undetectable viral load is a good sign.

Young people and young adults – it is recognised that age definitions are often somewhat arbitrary and variable. These terms are used to refer to the different groups consulted by the Network, as defined below.

## Project methodology

### *Literature review*

The Children and Young People HIV Network undertook an initial literature review, *Young people living with HIV and the transition from children's to adults' services* (Howell and Hamblin 2011) to map current thinking about transition for young people living with HIV and learning from other health conditions.

### *Focus groups for practitioners*

The Network then consulted 123 practitioners through a series of focus groups exploring what young people living with HIV needed at different ages; how services for them worked; what the challenges were in supporting young people through transition; and what solutions had been identified. There was representation from across England and also Wales. Variations in job roles, employment arrangements, and set-up of services make it difficult to categorise participants precisely, but in basic terms, 59 per cent were employed by the National Health Service (NHS); 27 per cent by voluntary organisations; and 14 per cent in statutory social care. Whilst all participants had contact with young people, about six out of ten worked in services that primarily focused on supporting individual adult clients or patients. A number of practitioners who were unable to attend focus groups also contributed.

### *Consultation with young people and young adults*

The challenges reported by practitioners provided a framework for the design of consultation sessions and individual interviews with young people. A small group of young people was consulted prior to designing group sessions and the first interview was a 'trial', with the participants informing future sessions.

Group consultations and individual interviews were organised in conjunction with voluntary organisations and health practitioners. Efforts were made to include young people with a range of characteristics and experiences; however, it is acknowledged that participation was greatest from young people with vertically acquired HIV who were engaged in some form of peer support, and of course taking part required young people to feel able to discuss HIV. For at least two people, the context in which they participated in this project was their first experience of meeting people their own age living with HIV. More females than males took part, so female perspectives may emerge more clearly than male in the findings.

A total of 45 young people and young adults contributed their experiences and views on transition, 35 through group consultations and 10 through individual interviews.

Gender/Age of participants	Young people aged 13–19 years	Young adults aged 20–28 years
Male	14	2
Female	19	10

Seven of the 10 people who took part in the one-to-one interviews lived in regions where youth-focused services from HIV organisations existed. The 10 young people accessed their HIV care in a range of paediatric and adult settings, and some were in the process of moving to adult clinics.

There were inputs from young people living in at least seven of the nine regions of England.<sup>1</sup> One interviewee lived in another country within the UK.

### ***Consultation with parents and carers***

A small-scale consultation with parents and carers was also organised with a voluntary organisation, and publicised via HIV sector networks. Four parents and carers of HIV positive young people attended. The HIV positive young people in their care ranged from the ages of 10 to 20; the parents also had children who were uninfected.

The consultation aimed to gather some insight into some parents' and carers' perceptions of young people's needs during transition and their own roles in meeting these; experiences of how HIV services work with young people and families; and the impact of young people's transition on the wider family.

There may well be scope for further exploration of parents' and carers' perspectives and needs.

---

<sup>1</sup> The regions currently defined for statistical purposes: North East; North West; Yorkshire and the Humber; East Midlands; West Midlands; East of England; London; South East; and South West.

## An overview of young people living with HIV

The geographical distribution of individuals in all three groups described below is similar: 42–53 per cent in London; 88–92 per cent in England as a whole; 4 per cent in Scotland; 1–3 per cent in Wales; and 1 per cent or fewer in Northern Ireland (Collaborative HIV Paediatric Study 2011; Survey of Prevalent HIV Infections Diagnosed 2010a and 2011a).

### ***Children and young people accessing HIV care in the UK and Ireland***

In March 2011, the Collaborative HIV Paediatric Study (CHIPS) reported that 1,190 HIV positive children were alive and receiving HIV care at a CHIPS clinic; an additional 305 had transferred to adult care. In 97 per cent of these 1,190 cases, vertical transmission was identified as the route of infection. 79 per cent of these children and young people are of Black African ethnicity<sup>2</sup>; of the remaining 21 per cent, 50 per cent are of mixed heritage and 28 per cent are white. Just over half of the children were born outside of the UK and Ireland. The balance of males and females is almost equal.

The proportion of young people in paediatric follow-up aged 10 years and over has increased from just 11 per cent in 1996 to 70 per cent in 2010. In 2010, the median age of this cohort was 12.4 years. There were 258 young people over the age of 15 receiving paediatric care in the UK and Ireland in 2010, and 416 people aged 10–14 (CHIPS 2011).

### ***Individuals aged 16–24 accessing HIV care in the UK: 2010***

Historically, the proportion of people living with HIV in the UK who are aged 16–24 has been relatively stable (Health Protection Agency 2007). The Survey of Prevalent HIV Infections Diagnosed (SOPHID) recorded that, of 69,424 people diagnosed as HIV positive and attending HIV clinics for care in the UK in 2010 (SOPHID 2010b), 2,353 were aged between 16 and 24 years. Of these, 543 were aged 16–19 (SOPHID 2010a).

According to SOPHID (2010a), 44 per cent of individuals in this group of 16–24 year olds are white and 38 per cent are Black African. The three main transmission routes for the total group were heterosexual sex (38 per cent); sex between men (33 per cent); and vertical transmission (22 per cent). In 2001, only 2.5 per cent of young adults accessing HIV care were infected vertically. Infections attributable to injecting drug use are extremely rare.

### ***New diagnoses amongst individuals aged 16–24 in the UK: 2010***

SOPHID recorded 6,658 new HIV diagnoses in the UK in 2010 (SOPHID 2011b), 677 of which were in 16–24 year olds in the UK in 2010 (this

---

<sup>2</sup> It is important to recognise that the Black African community is in itself highly diverse.

number may rise as further diagnoses are reported). One in five of these young adults were aged 16–19 at diagnosis; 56 per cent are white and 22 per cent are Black African (SOPHID 2011a).

Whilst over half of new diagnoses in young adults were in men, three-quarters of diagnoses of heterosexually-acquired HIV were in women (SOPHID 2011a), although women are often diagnosed at an earlier stage than men, partly due to antenatal testing. However, Health Protection Agency (HPA 2010) data suggests that rates of *recent infection* amongst diagnosed heterosexual women are highest in the 15–24 age group.

## The health and well-being of young people living with HIV in the UK

### *A general picture*

Foster and others (2009) undertook an analysis of the 654 young people over 10 years of age followed up in CHIPS between 1996 and 2007. Many of the findings on the health of young people had implications for transition. The median age of transfer to adult care was 17. Significantly, 38 per cent of those who had transferred to adult care had had an AIDS defining illness; a quarter entered adult care with severely compromised immune systems. Over half of young people for whom data was available had developed resistance to at least two classes of antiretroviral drugs: this has consequences for their future treatment options.

In a case note review of 63 young adults with vertically acquired HIV infection, Frize and others (2011) found that over half the group had clinically significant psychological issues. These were more prevalent amongst young women than men, although young men with psychological issues were more likely to decline interventions.

Research on neurocognitive impairment in this cohort has highlighted the need for a more robust body of evidence (Paramesparan and others 2010).

### *Adherence to antiretroviral therapy*

Achievement of good treatment adherence is frequently cited as one of the key challenges in the provision of healthcare to young people living with HIV. Patterns of adherence set in childhood may set a precedent for adherence in adulthood (Kent and others 2011). In a survey by McDonald and others (2011), 138 young people reported on their adherence to HIV treatment. Good adherence was reported by 63 per cent of respondents. The two most important factors young people identified as supporting adherence were reminders from family/carers and peer support. Forgetting and being busy were the most commonly mentioned barriers. The research revealed that 'stigma and secrecy remain a barrier to adherence for one in five of the young people surveyed'.

### ***Sexual and reproductive health and sexual behaviour***

Croucher and others (2011) undertook a case note audit of 51 people aged 16–25 with vertically acquired HIV infection, all of whom had accessed one clinic between 2005 and 2011. Of these young adults, 77 per cent of females and 62 per cent of males had reported being sexually active. The median age at which they first had sex was 16 for both young women and men. Of the sexually active young women, 92 per cent reported using a condom the last time they had sex.

HIV charity Body & Soul has also presented evidence from a 2011 survey of 50 clients aged 13–20: this included young people who are affected by HIV as well as clients who are HIV positive. Of the half of respondents who reported being sexually active, the median age at which they said they had first had sex was 14. Over 60 per cent reported using condoms all the time (Smith and Body & Soul 2011).

An article by Paula Seery, 'The sexual health of young people in the UK who acquired HIV at birth' (2010), describes how young people living with HIV are affected by many 'factors that have been associated in the generic sexual health literature with adolescents engaging in more risky sexual behaviours', such as poverty. Seery illuminates a wide range of possible sociocultural, physical and psychological influences on the sexual health of these young people, such as fear of disclosure and body image concerns.

Young people living with both vertically and horizontally acquired HIV are having children. In 2010, the HIV in Young People Network (HYPNet) conducted an audit on pregnancy outcomes in 172 young women who had acquired HIV vertically or in early childhood. Thirty-six pregnancies were reported in 27 individuals aged 14–29. Of the 36 pregnancies, 75 per cent were unplanned, 86 per cent involved regular partners, and in 61 per cent of cases, partners were aware of the woman's HIV status. There were 18 live births (six infants born prematurely); five miscarriages; nine elective terminations; and four ongoing pregnancies. None of the infants had tested positive for HIV at the time the study was presented. The researchers found that 'treatment adherence and virological control was sub-optimal during pregnancy' and 'two-thirds of the young mothers had complex social needs with one quarter of their offspring requiring foster care' (Williams and others 2010).



## Policy and practice guidance on transition

This section is based on a more detailed section in the Children and Young People HIV Network's initial literature review (Howell and Hamblin 2011).

### General guidance on transition

*All young people are to have access to age-appropriate services which are responsive to their specific needs as they grow into adulthood (Department of Health, 2004).*

This aspirational standard for transition is set by the *National Service Framework for Children, Young People and Maternity Services: Key issues for primary care*. The NSF states that multi-agency transition planning for young people is key to providing high quality transition services. *You're Welcome – Quality criteria for young people friendly health services* gives best practice guidance and states that services should have specially trained staffed and clear procedures to prepare young people for transition from an early age, with specific attention given to those with chronic, long-term conditions:

*Appropriate staff members are trained to help young people, and their parents or carers, with the transition to adult services from the age of 12 onwards (Department of Health 2011).*

Young people should be offered appropriate information and advice, which is easy to understand, to help them make safe choices around sexuality and health. They should also be helped to develop the confidence and skills to negotiate relationships and to delay early sex and resist peer pressure. The Royal College of Paediatrics and Child Health, in *Bridging the Gaps: Health Care for Adolescents* (RCPCH 2003) stresses the importance of careful preparation and planning, of consulting with, listening to and empowering young people in preparing them for this important transition in their lives. *Transitions: Young Adults with Complex Needs: A Social Exclusion Unit Final Report* recommended the following as principles of service delivery for young people in transition:

- *actively managing the transition from youth to adult services;*
- *taking thinking and behaviour into account, and building on it;*
- *involving young adults (and their families and carers) in designing and delivering services;*
- *giving effective information about services, and sharing information between services; and*
- *offering young people a trusted adult who can both challenge and support them (Office of the Deputy Prime Minister 2005).*

## Guidance on transition and HIV

The Children's HIV Association of the UK and Ireland has produced *CHIVA Guidance on Transition for adolescents living with HIV* (Foster 2010) as well as guidance on other topics relevant to transition. The transition guidance relates to health settings and is informed by learning from transition for young people with other health conditions. It provides an overview of issues faced by young people living with HIV, and outlines different service models. It states that 'preparation for both the young person and the family can begin when an adolescent is fully aware of their HIV diagnosis'. Transition 'should be centred around the needs and wishes of the adolescent' and the family should also be offered support and sources of further information and advice. The guidance recommends that 'each young person should have a documented transition plan in their notes' which can be used to manage the practical, social and emotional issues that commonly attend greater independence, including information on sexual health and development. Details of what should be included in a transition plan are given. These focus on young people's knowledge, understanding and competency; their opportunities to develop autonomy and become familiar with adult services and staff; their wishes and views; and practical aspects of transferring their care.

In line with other guidance and research on the subject of health transitions, this HIV-specific guidance states that transition should be seen and experienced as a *process* rather than a fixed point in time, requiring a flexible approach and a multidisciplinary response based on the young person's individual needs, awareness and abilities.

## The changing concerns of young people living with HIV

In one consultation session, small groups of young people of mixed ages were asked to explore key events, needs and experiences relating to a hypothetical HIV positive young person at the ages of 13, 16 and 19. This is what they said.

Young people felt that 13 year olds living with HIV would be developing freedom but also greater responsibility, and experiencing increased pressure with 'more stuff to remember'. They were thinking about GCSE options and transition. The group felt that 'influences come more from friends and family' and discussed 'good' versus 'bad' influences. Trust and bonding in relationships were important. Identity was being formed: 'beliefs change – like becoming an emo'. Physical factors associated with puberty were mentioned, as well as pills and forgetting to take them.

At 16, most of the same concerns still applied. Two key issues were sexual and reproductive health, and disclosure to friends. Sexual relationships in general were considered to be important to 16 year olds living with HIV, as were friends, 'breaking friendships' and a 'change of morals'. Education, careers and leisure time were all important. Negotiating control over personal HIV information came up, as did dealing with different people within the family knowing and not knowing. Young people talked about 16 year olds realising the truth and its impact, and blaming others and themselves. Self-harm and depression were potential issues, as was feeling 'fed up with taking meds'. At 16, anger at other people's ignorance about HIV was identified as a concern. The mention of health insurance reflected developing awareness of practical aspects of adult life with HIV.

The group considering the needs of a 19 year old came up with similar ideas, with an emphasis on independence and responsibility. Work, university and getting a driving licence were important.

## The adult lives young people want

### *Young people*

Young people in interviews were asked about any ideas or hopes they had for their future, and prompted with some aspects of life to consider. In order of frequency, they mentioned wanting to go to university or being there already; wanting children; aspiring to specific potential careers; achieving a certain standard of living (e.g. 'a big house and a big yard and a big car, everything has to be big, everything has to be on point'); and living abroad for some time.

The young people were then asked what things they thought they might have to deal with (not necessarily in a problematic way) in order to achieve their goals. Three people mentioned the need to do well in education. Three expressed uncertainty about the career paths they were attracted to, due to

competitiveness, lack of job security or perceived restrictions on employment of people with HIV:

*I obviously have dreams and hopes but some of them have to be put on hold because before I knew of my status, I thought, 'Wow, I can do anything,' and like now I'm just like, 'Wow, I'm going to have to think about what I'm going to be able to do,' because there are some things that are limited like you can't be a pilot and be an air hostess.*

Two people identified HIV-related travel restrictions as potential obstacles.

One person mentioned the need for contacts; another said, 'I've kind of used the contacts that [my status] can bring like to get [...] work experience and stuff like that.'

For two young people, proximity to HIV services was a factor in choosing a university. One person needed to know that 'I get to the uni where I know that there's going to be support around me [...] I'm not far away from home, I'm not far away from my hospital.'

Four young people discussed how being HIV positive affects having children; HIV was referred to more as a consideration than a barrier. Four people felt that disclosure to partners made, or would make, getting into relationships difficult:

*I want to find someone, but, I don't know. I don't know. [...] It's just HIV that holds me back.*

*I do want a family but not, I don't know... I wouldn't know how to tell anyone. That's one thing that I've never told anyone.*

Four young people specifically talked about being able to do whatever they set their mind to, or not being 'ruled by my status':

*My grandmother lives in Africa where it's a Third World country. My mum moved here to have a better life and now I've experienced that better life but to me it's the same as my mum and her mum and the Africa situation. So, for me, I have to move away from that situation of my mum and go somewhere greater so that my kids can aspire to greatness as well.*

This person emphasised the need, when living with HIV, to be determined:

*What you should say is, 'I've got HIV, oh well, I'm not going to limit myself by not getting an education. I'm not going to limit myself by saying no, I'm not even going to try that.' [...] If I was not HIV positive, I would not be here right now [...] meeting new people.*

### **Young adults**

Eleven young adults were asked about their hopes and ambitions for the future. Their answers were: entering into a particular career (6); having children or bringing up their children (5); being in a loving relationship or marriage (4); having or buying the home they wanted (4); travelling or living abroad (4); helping others or contributing to society through work (4); educating themselves (3); inspiring or educating others (3); writing a book (3); moving home or resolving a housing issue (3); finding work (2); having more or enough money, or paying off debts (2); providing their children with an excellent education (2); owning a business or enterprise (2); learning to drive or getting a car (2); being in good health; quitting smoking; being cured of HIV; and 'becoming stronger'.

Some comments were:

*Seeing my son grow up.*

*I want to move out of my mum's house – I don't feel safe.*

*Be an ambassador for HIV.*

*I can't see the future. There is too much right in front of me.*

Young adults were then asked about what challenges or obstacles they faced in achieving their goals. Their answers related to many areas of their lives: health issues and/or being on treatment (4); lack of work opportunities (3); negative or destructive relationships with or influences from friends, partners or family (3); lack of money (2); parenting an HIV positive child; the need for child care; lack of sleep; lack of emotional support; lack of information; the possibility of reoffending; and the council. They also often mentioned being held back by their own feelings and behaviours, including poor organisation or time management (3); poor financial management (2); laziness (2); depression (2); stress; fear of HIV status being known by others; fear of rejection; fear of re-entering education; taking on too much; stubbornness; unhealthy lifestyle choices; lack of confidence; 'not letting people in'; and 'lack of morals'.

Some of their own words were:

*Dealing with my daughter's status as she gets older. I'm not sure how I will manage that.*

*Being able to stop crying.*

*Other people putting me down when I'm trying so hard to do my best.*

Lastly, the young adults, all of whom were engaged with voluntary sector support, were asked what could help them achieve their goals. This included assistance from others but also included skills and practical tools. Sadly, one person said, 'I don't have any tools. I don't know what can help.'

Others had plenty of ideas including: their HIV support organisation (5); family (4); money (4); friends (3); support with child care (3); a job (2); professionals (2); love and acceptance; a current partner; qualifications; work opportunities; careers advice; financial advice; counselling; support for carers; volunteering; 'me time'; and 'people with the same dreams'. They also identified qualities to develop in themselves: life skills (2); keeping busy and active; talking more to overcome low confidence; listening to advice; and motivation.

The young adults in general seemed to express greater distress than the younger people when talking about their lives. However, this was a small number of young adults, and it is possible that they found it easier to be open about their feelings.

## Support available to young people during transition

The transition experiences of young people, and the experiences of those working with them, vary widely across the country. Local populations of people living with HIV also reflect differences in the demographic make-up of communities and, notably, the age distribution of children and young people living with HIV varies between areas, perhaps due to trends in immigration and dispersal of asylum seeking families.

The configurations of all services working with young people are influenced by local demographics, organisational or local service structures, client needs and available resources.

## Health services working with young people

### *Services provided to young people*

A wide range of professionals may work with young people who are living with HIV within health services, including but not limited to consultants; nurses; psychologists; health advisers; pharmacists; dieticians; social workers; counsellors; and antenatal care professionals. Several clinics have also begun peer mentor programmes in partnership with the voluntary sector.

Many health practitioners are specialists in HIV but some are not. Other practitioners are often involved in providing services beyond young people's main HIV care.

Doctors working with this group may be Consultants in Paediatric Infectious Diseases (ID); Consultant Paediatricians with a specialist interest in HIV; or specialist Consultants in ID or GUM departments. Care may be shared between a local doctor and one from a more specialised service further away. Nurses may be paediatric or adult-focused and may have various roles, most commonly Clinical Nurse Specialists but also Nurse Consultants, Community Nurse Specialists and others. A small number of practitioners have an explicit specialism in adolescent HIV care.

Practitioners' remit to work with people of different ages vary. Young people usually access care in paediatric outpatient departments, children's hospitals, GUM departments, or adult ID departments.

Very occasionally general practitioners (GPs) will play a role in providing HIV care; at the other end of the scale, many young people's GPs are not aware of their status. Likewise, school nurses are only occasionally aware of an HIV positive pupil's status.

It is important to acknowledge the coordinating and support staff working in clinics who, in particular, play a role in making young people feel comfortable and engaged with health services.

Occasionally, paediatric services are able to offer support groups or events to enable young people living with HIV to benefit from group work and to discuss HIV outside a clinical setting. Health practitioners also often work closely with colleagues from the voluntary sector, in particular Paediatric HIV Clinical Nurse Specialists.

Here we see quite a complex picture of healthcare and support provided to children and young people across the country. This also indicates a broad range of experience and specialism in the care of children who have grown up living with HIV.

### ***Transition pathways within health services***

There are a range of possible health transition pathways for young people. An individual might:

- move from a separate paediatric service to an adult service usually within the same trust
- move from paediatric to adult services through a transition clinic designed specifically for adolescents and young adults
- attend a family clinic where children and adults are seen together, either from early childhood or adolescence, then move to an adult service that has become familiar
- access specialist paediatric HIV care at a regional centre before moving to a more local centre for adult care
- access care at a children's hospital before moving to an adult service in a different trust, usually one with which the children's service has an established relationship.

Some individuals who move areas transfer their care to their new location; others prefer to return to their familiar centre for appointments.

A British HIV Association survey of 143 adult HIV clinics/departments provides a national picture of transition arrangements from late 2009 (Curtis 2010). Of participating sites, 44 per cent had received young people with HIV transitioning from paediatric care and 50 per cent expected to do so. The remaining sites either expected transitioning patients to go elsewhere or were unsure. Almost 30 per cent of centres which had experience of transitioning patients had received 1–3 patients; a handful of centres had received more than 10 patients.

There was variation in the involvement in service planning of particular teams and stakeholders, including young people, at different sites. Of the 134 sites with or expecting transitioning patients, 36 per cent said there was a multidisciplinary group to oversee transition and 34 per cent had a named professional responsible for transition.

The most common age for first attending adolescent, transition or adult clinic was 15–17, and the most common age for discharge from paediatric care was 16–17, though this often occurred over 18.

Approaches to aid transition included key workers (61 sites), multidisciplinary meetings about individual patients (48), a family clinic



(29), a transition clinic (13), an adolescent clinic not specifically for transition (7) and patient-held health/life story summaries (7).

Five sites had had transitioning patients who stopped attending, and 39 had patients who attended irregularly. Support to improve attendance at clinic included following up missed appointments, having named contact workers, community-based nurse visits and the use of 'contracts' with young people.

## **Voluntary sector services working with young people**

### ***Services provided to young people***

Voluntary organisations play a central role in providing psychosocial support to many young people living with HIV. Practitioners working within voluntary organisations may be qualified social workers or education professionals, support workers, youth workers, counsellors, service coordinators or directors, or others with relevant experience. Volunteers may also be involved.

Services provided by voluntary organisations include age-appropriate peer support; education and confidence-building around living with HIV; counselling; mentoring; disclosure work; advice and support around learning, employment, healthy lifestyles, benefits, immigration and law; advocacy; financial support; creative workshops; physical activities; complementary therapies; day and residential trips; assistance with attending clinic appointments; crisis intervention; education and outreach work; and signposting to other services. Some organisations are able to offer some support via phone and email. Web-based information and/or social networking sites have also been developed by several organisations. Individuals may also access HIV information services and resources not specifically designed for young people.

Individual support from voluntary sector organisations may be formalised and more or less intensive, or *ad hoc*, as appropriate. Regular meetings (from fewer than ten young people meeting in school holidays to weekly meetings of around 60 people), one-off projects and residential camps provide opportunities for group work. Groups may be open to young people living with HIV infection only or may also include young people who are affected by HIV. In the second instance, a member's disclosure of his or her own HIV status is optional; sometimes sessions may be run solely for those who are HIV positive.

### ***Transition pathways within voluntary sector services***

From the focus groups, it appears that there is a widespread pre-requirement that members are aware of how HIV affects them before they participate in group work for adolescents. Disclosure work with families is often available prior to individuals joining groups; some organisations combine this with running groups for pre-adolescent children in which HIV is only openly discussed in smaller groups of children who are aware of how HIV affects them.

Voluntary organisations are generally not rigid about enforcing age limits for access to services where they identify needs, and although difficulties in providing ongoing support for young adults whilst promoting independence were discussed, 'cut-off' points at which services are withdrawn have not been reported so far. Participation in existing HIV support groups for adults appears to be almost unheard of amongst young adults who have grown up living with HIV, and rare for young people with horizontally acquired HIV infection. Adult-focused support services that do not work with young people themselves may visit or otherwise input into more youth-focused services.

Many young adults, with changing lives and new commitments, 'drift' naturally: finding that support received in their teens stands them in good stead for young adulthood, or that attending groups on an occasional basis and/or returning for one-to-one support at particular times or with specific issues suffices to meet their needs. Special groups for young adults are generally not a possibility, although Body & Soul runs a regular group in London. However, young adults are widely encouraged, if they wish to stay in touch with a familiar young people's group, to take on leadership roles and volunteer to support younger members.

## **Statutory social care services working with young people**

### ***Services provided to young people***

Some young people living with HIV have access to support from statutory social care services based in local authorities or integrated into health services. Eligibility may be based on where a person lives or accesses HIV care. Children and families social workers specialising in HIV are exceptionally rare within statutory services. Specialist HIV social workers for adults have varying flexibility to work with young people, and some do so in the context of whole-family work where parents or carers are the link.

Young people are more likely to be worked with by children and families social workers with a broader remit, e.g. child protection, fostering, or disabilities. This work may be related to aspects of a young person's life other than HIV. Social workers may or may not be aware of an individual's HIV status, and may or may not have experience of working with people living with HIV.

Some young people living with HIV are in the care of their local authority, although it is not possible to provide a reliable estimate of how many.

### ***Transition pathways within statutory social care services***

Young people who do receive support from child-focused HIV specialist social workers may find that, upon reaching adulthood, they do not meet the eligibility requirements for access to adult services. Adult-focused social workers working with parents and carers, who may provide whole-family support, cannot do individual work with young adults without them being clients in their own right. Increasingly, young adults living with HIV who do

not have critical care needs will find it particularly difficult to access support from adult social care services.

Local authorities have legal duties to support children in public care with their transition from care to independent adult life, and should provide access to support until the mid-twenties.

## Other services working with young people

Like all young people, young people living with HIV may come into contact with a huge variety of agencies and professionals. Those mentioned by practitioners in the focus groups include education professionals; voluntary organisations not focused primarily on HIV (e.g. LGBT organisations); advice services; youth workers; faith leaders and groups; counsellors; immigration authorities and services; sexual assault services; the police; prisons and probation services; careers advisers and employment services; housing and benefits services; drug and alcohol services; fostering agencies; and interpreters. People working in these areas are often unaware of a young person's HIV status, but when they are aware, this knowledge can variously improve or impair the way they work.

It must also be noted that employers and prospective employers, whilst not services, can be very important in young people's lives.

## Young people's role in supporting each other

Many young people, practitioners and parents and carers felt that for young people living with HIV, opportunities to meet peers in the same situation were invaluable and could be central to a smooth transition to adulthood.

### *The benefits of peer support*

The young people interviewed had varying amounts of experience of peer support, and practitioners described young people with widely divergent levels of interest, willingness and confidence to engage with it. Young people who did were clear about what they got out of these opportunities:

*A lot. A lot. I can't even begin to describe [...] You can just be you and everyone there loves you for who you are and it's time to take medication and everyone's doing it at the same time. I'm a single child and obviously most of the time, like, if I'm taking medication, it's a bit depressing.*

*I like the idea of coming here and like being able to talk about our status just normally, like, sometimes when we're in our rooms we actually do just talk about whether if we had like the opportunity, say, a cure came to us. [...] If you had the choice to stop like you having HIV, would you or not? Then we think sometimes, yeah we would, but then sometimes [...] we wouldn't be able to meet people [...] And also I like the idea of like not having to hide my medication, so I could like just open my suitcase, take my medication in my hand and drink it in front of them. [...] I like being just free.*

*I have so much love coming from different ways when you come, meeting people who are just the same as you, who feel, who seek acceptance from the world but they don't know how to get it.*

Taking the first step to engage with peer support is not easy. One young adult's first experience of peer support came over a decade after learning his/her HIV status. However, once engaged, many young people appear to form lasting friendships which they maintain beyond the service setting:

*I actually have peers rather than mentors, which I think is a bit better to be honest. [...] It's easier to actually tell them everything that's on your mind, sometimes with a mentor you want to hold something back because there's like the professionalism and also, a lot of the time they may even be older than you.*

Young people kept in touch with friends from HIV services through a variety of means, although several struggled with this due to distance. The emphasis on friendships outside of support services was often on being like 'just normal friends from school or something' and whilst several of the young people could talk to these friends about HIV outside of service settings if they wanted to, their responses showed that, for most, conversations about HIV were harder or less relevant or necessary outside:

*We won't really talk about it much when we're out because we're probably going out to do something, like go cinema, so we probably won't even be thinking about that at the time [...] But if the conversation does come up, we'll just be talking about it.*

*There's one friend that goes to the group that like I will openly talk to them about it, but then the rest, I'm friends with them but not like close enough to just come out and say it.*

*I speak to them all the time, they're like family [...] I do talk to them about HIV, like, sometimes [...] I'll just go on Facebook like, 'Hey, you all right? What are you doing? Are you alone?' [...] If they're with friends, I won't say anything but if they're alone then I'll spill the guts out! I make sure that they're comfortable as well as I am.*

One person acknowledged the need to let younger people 'have a turn', and several people had a sense of their potential, as they got older, to support their younger peers, also recognising that this could bring some value to them themselves:

*I'm not going to stop going to the group because I want to help others as well [...] I'd be stopping to being a young person but then I'd be a peer mentor, so I won't really stop, I'll just upgrade.*

*I feel like I get something because I'm talking to them, I'm sharing my life story so, yeah, I do get something, I do get to teach them.*

Interestingly, three young adults said that they would like to write a book, though not all specified what type of book. One person intended to write a book showing that 'it's a very long journey, but I've come out on top'.

It was felt that having been able to read such a book would have been helpful growing up: 'That's what I needed.'

Younger members of groups do seem to value having role models in older members. In one group consultation, young people said that being in groups with people a few years ahead of them helped them prepare for 'what you're going to face'.

### ***Young people who do not access peer support***

Difficult feelings about living with HIV can preclude engagement with peer support. Practitioners agreed that all young people should be given information about services and help to overcome barriers to accessing them, but said that sometimes reservations will remain. Several practitioners emphasised that peer support is not for everyone and that young people's choices must be respected. Some young people may prefer to get support in other ways. One parent/carer mentioned a practical barrier to engaging with peer support, in terms of a young person's fear of photographs being taken amongst the group and ending up on social networking sites.

## **Sources of support described by young people**

Young people identified various forms of support as being available or important to them.

### ***Support around living with HIV***

The sources of support most frequently mentioned by young people were parents, specialist HIV doctors and nurses, and voluntary sector practitioners or services. Siblings, other family members, friends, partners and in one case adults living with HIV outside the family were also identified.

One young person mentioned a social worker: 'When I need to go to hospital, I have my social worker take me and she comes in with me to any appointments.'

Pharmacists and dieticians were mentioned by one group, who also identified a few non-specialist health services, such as contraception services. This group found GPs unhelpful, and also teachers. In one interview, a young person whose HIV consultant was based in a different region described a GP as useful for answering 'quick questions'.

Books, websites and DVDs were identified as helpful by some young people.

### ***Support in other areas of life***

The 10 young people interviewed individually were asked to consider whether they felt particular services, authorities or agencies that young people might come into contact with had been important in their lives, choosing from a list of areas. These were education (which 10 people identified as important); work and careers advice (7); money and benefits

(4); housing (4); social services and care (1); immigration (0); law and crime (0); and drugs and alcohol (0).

Voluntary HIV organisations provided assistance in these areas to several people. One young person was even introduced to his/her employer through a support organisation: 'There was a [fundraising event] and the gentleman, my boss now, was there and then he said that he would like to stay in contact with me [...] He's just cool so I can speak to him about [HIV] if I want.'

The social worker supporting one young person with living with HIV (see above) was mentioned again: 'Whenever I need help with like applying for uni and applying for anything, I usually just call her to help me.'

When asked if anybody gave them information or helped them think about their future lives and options, young people most frequently identified family and voluntary sector organisations or practitioners. Doctors, nurses and friends were also mentioned, as well as the internet and written information sources.

### ***Support for young adults***

Young adults were naturally aware of a wider range of services and agencies although one person in particular felt let down by some of these. She was a pregnant mother:

*I live in a one bedroom flat that's infested with mould. [...] I've written to my MP, [...] letters from my midwife, my HIV specialist... nothing helps. [...] The mould is making me sick as well. In the past year I've been hospitalised five times because my immune system is suppressed. [...] I'm scared... What if my baby dies from the mould? [...] They're driving me mad.*

Young adults were asked what they needed to help them achieve their goals. This included support from others but also included skills and practical tools. The full range of what the young adults said they needed is set out above, in 'The adult lives young people want'.

## Experiences and challenges

A range of challenges to successful transition was identified by practitioners, young people and parents and carers, and these were highly interconnected and influenced by individual feelings and circumstances as well as local service landscapes. This highlights the complexity and importance of getting transition right.

Practice examples given throughout these sections are interventions mentioned in focus groups that seek to address some of the needs described.

### Key messages

#### *'Just normal young people'*

All groups consulted emphasised the importance of recognising that young people living with HIV are young people first. One young person put this very clearly:

*HIV is not me, HIV is a part of me. I'm not a part of it. So like it's basically like a cold. It's just a long forever cold, really and truly, that's all it is to me. [...] I just think sometimes in like services [...] they just need to realise that HIV is a part of you but that's not the only thing that might bother us [...] It's a clinic for young people and you're there to talk about HIV but if you talk about it so many times, it gets annoying. It just gets annoying so I don't care any more [...] I know I've got HIV. Cool. But [...] we're young still! We're just normal young people.*

For most of these young people, living with HIV *is* their normality: 'Growing up with it, it's the only life you know.' It is important not to assume that problems exist where they may not: some young people living with HIV reach young adulthood without experiencing many of the challenges described in this report. Where young people have faced difficulties, these will not necessarily have made them vulnerable but may have built their resilience.

#### **Stigma**

HIV-related stigma was identified by all groups as leading or contributing to many challenges. There was wide recognition of the difficulty of tackling stigma, but a sense that doing so would contribute to addressing most of the other issues identified. Balancing young people's need for strict confidentiality with the need to avoid further entrenching stigma by treating HIV as a 'secret' was a key concern for practitioners.

### ***Poor adherence and loss to follow-up in healthcare***

Poor adherence to treatment and engagement with services were consistently identified by practitioners as causes of concern, and seen as consequences of many of the issues below.

Practitioners commonly believed that negative experiences of disclosure and transition can contribute to difficulties later on.

### ***Funding and workload***

Worries around funding and workload were raised by practitioners working in all disciplines and areas. Many focus group participants expressed clear ideas about how young people could be better supported, but felt that insufficient time and resources prevented this from happening.

### ***Meeting the full range of diverse needs***

The difficulty of meeting the unique needs of all young people living with HIV was discussed by practitioners, especially in areas of lower prevalence. How well a person fits in to and has their needs met by a service will depend on a range of characteristics of the wider client group. Some individuals may find that there is no youth-focused HIV service that can meet their exact mixture of needs because they belong to small minority groups within a cohort which is small itself. For some young people there are very practical barriers to accessing support, including language barriers, living arrangements, and other practitioners involved in their lives. Young people in public care, who tend to leave home younger and grow up more suddenly than their peers, may also struggle and not benefit from the supportive family relationships highlighted as important by young people. Practitioners also identified working with young people in the youth justice system as a particular challenge.

## **Talking and learning about HIV**

### ***Disclosure***

For an HIV positive child, knowing his or her HIV status and what this means is a crucial prerequisite to becoming more independent. Current practice is to manage disclosure as a process, preparing a child for the naming of his or her diagnosis in line with CHIVA guidelines *Talking to children about their health and HIV diagnosis (Melvin and others 2008)*. These guidelines recommend that HIV positive children should know the name of their diagnosis by the time they begin secondary school, unless exceptional circumstances make this inappropriate. Occasional cases of naming occurring significantly later, identified by practitioners and young people themselves, are a cause for concern. The main reason cited for this delay is parental resistance.

### **Young people's and young adults' perspectives**

Young people who were interviewed were asked about their experiences of learning their HIV status. Six young people reported having learnt the name



of their diagnosis between the ages of 10 and 13. Two people were unable to estimate an age and felt good about this. Two had learnt their HIV status at the age of 15 or thereabouts (both within the last three years): it is not possible to ascertain why this happened based on these interviews, but one person 'already kind of knew' and the other did not. For this individual, naming occurred at the point of starting treatment: although 'it was handled well', 'it was just afterwards, about a few months, as I was taking medicines, that's where it went wrong for me'.

For those who remembered, naming happened either at home or in a healthcare setting. Some young people had positive experiences of having their diagnosis named:

*My mum told me, I think it was within a week [...] of my next appointment. I think they planned that. So it was no more than a week until the next time I was going to see my doctor.*

*I was completely fine with it. But only until recently have I been kind of feeling odd about it and kind of realising, 'Oh, this is hard to cope with, I don't know how to deal with all this.'*

Others found that naming happened too abruptly:

*They just kind of came out with it, they didn't really do an introduction or give me any information about it [...] It wasn't until my next appointment that I was able to [ask questions].*

*My GP told me in a normal situation [...] He told me I couldn't tell anyone.*

One person was never told at all:

*I kind of guessed [...] and then I remember going on the internet and searching and then I was right. So that's how I found out, and then I just pretended I knew from the start but no one actually said, like, 'You've got HIV.'*

One young adult was glad she discovered her HIV status in early adulthood: 'I'm glad my grandma kept it from me. [...] At least I had a good childhood.' On the other hand, she acknowledged that, 'You never know when they will start to be sexually active. [...] I kept myself to myself, but I could have infected loads of people by then.'

Some young people mentioned how knowing their status affected their feelings about treatment:

*Ever since I was growing up, my mum would tell me little stuff about it [...] My mum was like, 'Oh, at first, like, you shouldn't maybe go around telling people' [...] I preferred like going along with it, like learning more information, knowing more about it, and then so I know what it is, like, not just me having to be curious all the time: 'Why am I taking these medications?' [...] Knowing what it was, it was easier for me to take the medication.*

Some young adults are having to think about disclosure in relation to their own children: 'I'm going to have to think about telling my son and I don't know how that will be'.

### **Parents' and carers' perspectives**

One parent compared the experience of her child with that of a relative in her care, now a young adult, who was diagnosed with HIV as a child of primary school age. Her own child was disclosed to at a younger age than the relative had been and asks questions, shares worries and 'doesn't see HIV as limiting'; whereas the relative learnt about HIV in the context of having lost a parent, been uprooted to another continent, and entered a new family set-up. This seems to have framed the relative's identity and perceptions of HIV. The parent/carer also mentioned that diagnosis of a child at birth enables his or her knowledge to be built up gradually from a young age.

### **Practitioners' perspectives**

Parents and carers may feel reluctant or anxious about disclosure to children for a number of reasons explored in depth in other pieces of work such as the CHIVA guidelines. Practitioners identified that, in cases where parents or carers have strong reservations, great sensitivity is needed to avoid disengagement from adult and/or children's services, which can pose a risk to parents' and children's health and well-being and to the smoothest possible adolescence for the child in question. This also applies in cases where children of HIV positive parents have not been tested for HIV. Where children of HIV positive parents are diagnosed in adolescence and parents do not want them to know their own status, practitioners said that helping the young person to understand their own diagnosis can be difficult.

It was noted that support services for young people in the pre-adolescent age bracket need to be able to manage the varying degrees of HIV awareness amongst members of groups, and potentially the different disclosure processes and experiences for infected and affected children if a group is mixed. Creating appropriate environments in HIV services was also raised as an issue, in terms of balancing openness about HIV and sexual health with managing children's knowledge.

### ***Learning about HIV and treatment***

Learning about how HIV impacts on sex, relationships and sexual and reproductive health is addressed further below.

### **Young people's perspectives**

One comment from a young person who gave an eloquent explanation of prevention of vertical transmission highlighted how difficult it is, even when highly engaged with learning about HIV, to absorb and retain all the information given, and the need to prioritise information which has most practical relevance:

*I asked! [...] I quizzed my doctor about everything. [...] I just said, 'You know what, let me just write all my questions down.' [...] And obviously [a voluntary sector service] as well, [...] you have workshops and stuff, you get to learn more. [...] Yesterday, I learnt that HIV – you know the 'Immune' bit? It has 'deficiency' in it as well. And I never knew that. I thought it was just 'Human Immune Virus'.*

Several young people commented on how voluntary sector services helped them to learn about HIV in an accessible way:

*Every time I go, I always get like a little something more that I didn't know [...] Like there's certain stuff I thought: maybe you can't catch it through this.*

One key factor here may be space and time, as highlighted by one person:

*Do it bit by bit. [...] One meeting or something you can talk about HIV, then the next meeting you can talk about, 'OK guys, how's your relationship?' Next we can talk about HIV with stigma or something. Do it in stages because it's not all about cramming everything in and chucking stuff at us every single time. [...] My mind is very, like, if you annoy me, I'll just block you [...] and I won't listen [...] and it will one day mean something more to me and I'll look back and be like, 'What did they say again?' [...] It means much more if you sit down, talk to me: 'This is what's going on. What do you want to know?'*

Young people commented on how they developed their grasp of medical terminology and the help they got – or didn't get – with this:

*She explains everything to me so I know exactly what's going on.*

*At the beginning it was a bit weird, like my dad not being next to me because normally he was there and he would be the one asking the questions like, 'How's my blood doing? How's my CD4 count?' etc. etc. So then now it's like up to me to like understand that. I understand what my doctor's saying as well now, so it's much better.*

Several people said they didn't like having to ask questions to understand medical jargon:

*When [doctors] use long words [...] I have to ask, 'What does that mean?' It makes me feel quite stupid.*

*I just feel like I'm just going to get my blood taken and I just lose blood and know about my viral load, that's it. But before, I felt like, 'I'm going to know something, I'm going to hear something new.' They used to say 'Oh, your virus is really good.' [...] [Now] they speak in doctor language.*

Written information, whether communicated on paper, online or via mobile phone, was sometimes welcome but sometimes caused fear of stigma or conflicted with a sense of duty to hide HIV from household members, for example uninfected siblings. Different individuals felt that different media

posed more or less of a 'risk', depending on the perceived privacy of their bedrooms, phones, bags, computers and internet histories:

*If things come through the post, family members who don't know I'm HIV positive might open it.*

### Parents' and carers' perspectives

One person who was bringing up two young people living with HIV with a wide gap in age found that nurturing the second child's awareness and understanding had been easier than the first time, having lived with HIV for longer as a parent/carer and become more knowledgeable and confident. The group agreed that having information and support themselves, as HIV positive adults, could empower them to help their children learn about HIV.

### Practitioners' perspectives

Practitioners highlighted that young people vary enormously in their readiness and capacity to engage with and understand information about HIV and its implications for their lives. Disinterest can be associated with denial or with positive adjustment to a life in which HIV is not the focal point. Young people may also say they understand information that is unclear to them to please others: the need to avoid medical jargon was acknowledged. One practitioner in an adult health service described how a colleague would swamp a particular patient with complex information on side effects, but the young person found this 'depressing' and only wanted to know, 'Can I drink alcohol? Can I still go out dancing?'

Communicating information about HIV in a non-threatening way is discussed as a fine art, particularly during the disclosure process and in relation to adherence to treatment and criminalisation of HIV transmission. In addition, it was pointed out that individuals may receive conflicting information from different sources, and that the internet in particular can be a breeding ground for misinformation.

Enabling young people to retain information about HIV is also a challenge, given the potential issues around written information resources.

### Practice examples: Developing and sharing appropriate information resources for young people

Enabling young people to lead the development of resources for young people is good practice, and this happens across the sector, with groups using a range of technologies and creative media. A number of websites aimed at young people provide information and share experiences and creative work. Faith in People with HIV's Pozitude website<sup>3</sup> is an example of online information on local services relevant to young people living with HIV in the area. Other websites, such as the CHIVA website<sup>4</sup>, provide or gather resources to inform or assist practitioners' direct work with young people.

<sup>3</sup> [www.pozitude.co.uk](http://www.pozitude.co.uk)

<sup>4</sup> [www.chiva.org.uk](http://www.chiva.org.uk)

## **Openness about HIV**

### **Young people's and young adults' perspectives**

In general, young people valued discussions about HIV at home:

*He's always there for me, he's always willing to talk [...] I just tell my dad everything and he tries his best to help me even if he doesn't quite understand what I'm going through.*

*If you're only going to have one support, it's better to have somebody in your family.*

Some people found it difficult that their parents or carers were unwilling or unable to talk about HIV:

*At the moment, no one [supports me]. My family don't really talk about it. It's kind of like a thing we only talk about when we're on our way to the hospital appointments or on our way back.*

*My dad, he's negative and he doesn't really talk about HIV at all, and he's reluctant to talk to me about it, because he thinks that – I don't really know what he thinks – I think he thinks I can't handle it, which is a bit weird seeing as I'm always like, 'Oh, I'm at [this organisation] this week, [...] I'm at [that organisation] that week,' so it's a bit like, clearly I can talk about HIV.*

It was common for some members of the family to know about a young person's HIV status and not others. Sometimes, young people were essentially forbidden from disclosing their HIV status to their uninfected siblings. There was some sense that hiding HIV felt burdensome and shameful; on the other hand, some people were uncomfortable with how disclosure to family members had taken place during their childhood: 'All of you knew and you left me there.'

### **Parents' and carers' perspectives**

The parents and carers expressed agreement that 'being as honest as possible helps' in relation to disclosure and discussing HIV, and saw openness as something families should aspire to. However, those attending a consultation session may feel more able to discuss HIV than some other people.

One person explained how Christianity had helped by providing a foundation to understanding, particularly in terms of stigma.

### **Practitioners' perspectives**

Difficulties accepting and discussing HIV within the family were identified by practitioners as an issue during transition, in terms of the strain they can put on relationships, hindering emotional support. Some practitioners also noted that families keeping HIV information from HIV-negative children can cause problems, creating divisions and secrets between infected and uninfected siblings, and putting affected children in confusing situations,

such as being brought to HIV clinic appointments with partial awareness of what is being discussed.

### ***Discussing sex and relationships***

#### **Young people's and young adults' perspectives**

Young people in one group consultation identified sex education as a key need for HIV positive 13 year olds, and mentioned criminalisation of HIV transmission. They felt that 16 year olds needed advice on sexual health and pregnancy, plus free contraception.

Some young people described finding it difficult to discuss sex at home:

*My dad has tried. He started and then I started to get awkward and then he started to get awkward so we stopped.*

Young people generally reported finding discussions about sex and relationships at clinic useful and well-handled:

*We've just got that relationship where I can just tell [my nurse] anything, anything at all, I just talk to her about it.*

*It's kind of all right because it's not so like, 'Don't do that, don't do that.' It's more advice instead of being strict about it.*

*Every time I have appointment, there is always that reminder [...] 'Do you have a girlfriend? Do you know what to do?' [...] I feel comfortable. I say, 'All right, OK, I remember, I know what to do.'*

Some people felt engaged with learning about sex and relationships but able to take control of when and how this was done in the clinic setting:

*My paediatrician [...] knew that it wasn't necessary like because [...] I guess I'm a late bloomer so I didn't really, I wouldn't have really wanted to hear it. But I was just like, 'No thanks, it's cool, like I'll learn next time I come in if I'm ready.' [...] I kind of went to him that I hadn't had sex and I didn't want to have sex any time soon so can we put off the conversation?*

Young people particularly appreciated being able to explore these topics with individual support workers and alongside their peers in non-clinical voluntary sector settings. One young woman who was the oldest member of her support group said: 'I tell them what's happened to me because they ask me like, "How come you've got a boyfriend who knows?" and "How did you do it?"'

Of the two people who said they had not really spoken to anybody about HIV and sex and relationships, neither accessed regular peer support and one was very geographically isolated. One said that doctors had never really mentioned it nor given advice on where to find information:

*I could ask my doctor but the only one I would probably be able to ask would be the one who comes up from [another region] and other than seeing her every six months we don't really speak.*

Remembering information that is not immediately needed can be difficult. One young adult had only recently become fully aware of how HIV positive people can have uninfected children:

*I've always known that I can have kids [...] and some of the percentages that I was told years ago that I don't really remember [...] One of the last appointments with [my paediatrician] when I was about 15, just kept on hammering in that I can still have kids [...] but I thought he was just saying it for saying it's sake.*

One comment highlighted how important it is that discussions around sexual health are not too narrowly focused on being HIV positive:

*[My doctor] made it clear that actually anyone should always use a condom ... Like anything was really possible [...] I hate the word - but you just kind of felt normal, rather than you should be doing something differently because of your status.*

### **Parents' and carers' perspectives**

The parents and carers discussed issues around sexuality for young adults living with HIV, including the legal context of prosecutions for reckless transmission for HIV and a sense that 'other young people are freely dating'. One young person was describing as having concerns around body image, being 'aware of physical differences [from] other family members' and doing 'anything to hide' despite being seen as attractive. Differences in whether and how sex and relationships were discussed at home were described as being linked to broader differences in a young person's general well-being and acceptance of HIV. Two young people were mentioned: one who, at a young age, freely asks questions about sex and another young adult who never asks anything. This small group of parents and carers did not express reluctance on their own part to have these conversations.

### **Practitioners' perspectives**

Feelings of awkwardness about discussing sex and relationships with young people were not noticeable amongst practitioners working in the voluntary sector, and many worked closely with colleagues in health services to provide accurate and accessible information. Knowing or suspecting that young people are engaging in sexually risky behaviour was a source of anxiety for practitioners in different settings, as was giving advice on risk of transmission in the context of the Swiss statement<sup>5</sup> on the one hand, and prosecutions for reckless transmission on the other.

---

<sup>5</sup> 'In January 2008, Swiss HIV experts produced a landmark consensus statement to say that HIV-positive individuals on effective antiretroviral therapy who have had an undetectable viral load for at least six months and without sexually transmitted infections (STIs) are sexually non-infectious.' (Pebody 2009).

Amongst health practitioners, those working in transition or young adults' clinics or GUM departments seemed most comfortable discussing sexual health with patients. Health advisers were highly valued. It was noted by some that training for paediatric practitioners does not provide adequate preparation for the task; in addition, if a patient has known paediatric staff since childhood, it may feel 'like talking to your parent'.

Professional perceptions of individual young people's sexual development and behaviour also provoked self-deprecating discussion around the tendency of paediatric staff to assume that a patient 'definitely isn't having sex yet' and of staff working primarily with adolescents or adults to jump to the opposite conclusion. This can lead to sexually active young people in paediatric care missing out on information and advice, and young people who are not sexually active being subjected to frequent discussions about sexual health that may feel intimidating or pressurising. Practitioners also noted the need to avoid assuming that young people with vertically acquired HIV are heterosexual. In addition, advice and support needs to take into account the influence of culture and faith: one practitioner observed how HIV disclosure and stigma impact on the marriage prospects of young people from communities in which arranged marriage is the norm.

Regardless of sexual behaviour or development, all young people need at least one individual with whom they have a personal rapport which helps them to discuss sex and relationships. It is also clear that this work requires specialist skills in order for it to be valuable and helpful for young people. For example, several practitioners noted the importance of framing conversations in relation to the young person protecting themselves as well as others, rather than focusing exclusively on the public health imperative.

It was noted that delivering group support for young people comes with a responsibility to address the potential for sexual relationships between group members by providing advice, information and condoms as appropriate.

Information about sexual and reproductive health given outside specialist HIV services was discussed. One participant described anger expressed by some young women with sexually acquired HIV at not having been targeted with awareness messages because they were not deemed 'high risk'. Another raised the issue of young people accessing sexual health services beyond HIV clinics without disclosing their HIV status: advice given in these contexts cannot be adapted to take diagnosed HIV into account appropriately.

Practitioners discussed how difficult it is for any parent or carer to talk to children about sex, and how HIV, with its links to sexual histories and consequences for future sexual relationships, can make these conversations exceptionally challenging. Cultural taboos were mentioned as compounding this further for many families. Feelings of blame were noticed as surfacing when young people with lifelong HIV infection begin desiring sexual relationships, which may be several years after learning their diagnosis.



**Practice examples: Supporting learning about HIV and sexual health**

Enabling young people to develop information resources for young people is a popular approach, as is inviting health practitioners to work with groups in voluntary sector settings. Young people also appreciate opportunities to ask questions anonymously. Keeping good records of when topics are discussed with young people has been highlighted as important.

**Access to appropriate services for young people*****Statutory social care***

Other than one social worker mentioned in 'Sources of support described by young people', young people did not mention statutory social care services.

**Parents' and carers' perspectives**

The parents and carers expressed the view that HIV was very different from other disabilities, and therefore specialist HIV social care services were valuable.

Parents and carers talked about responding to adults' needs as a prerequisite for responding to young people's needs, and how important it is to 'learn the practicalities of living with HIV' and not 'miss the fact that if you have a healthy parent or carer, you have a well looked after child'. This was particularly an issue in relation to accessing social care services. There was discussion around some of the difficulties parents and carers experience in meeting the criteria to access resources and support from social care.

While one person said that 'social services provided what I needed', others raised concern that assistance was not always forthcoming. For example, one person talked about going through a period of ill health and trying to get transport for her child to travel to school. Her experience was that social services took months to acknowledge the request, then 'every two days they chop and change on me' in terms of policies.

**Practitioners' perspectives**

Practitioners were very aware of difficulties families faced in accessing social care.

Relatively few practitioners from statutory social care attended the focus groups, which is indicative of the scarcity of specialist HIV practitioners in children's social work. Participants tended to be specialist HIV social workers for adults or children's social workers for whom HIV work was either part of a broader remit or circumstantial, arising in their casework. The commitment and input of social workers was highly valued by practitioners from all sectors, and there was a concern that the availability of appropriate statutory social care support for young people could be a lottery. In many areas it depends on non-specialist social workers having above-average HIV awareness and going 'the extra mile' with limited access to training or resources. Comments about time spent mentoring less

experienced colleagues, struggling against prejudice and misunderstandings within the workforce, and clamouring for funds to support this group suggested patchy access to HIV-sensitive statutory social care services for young people. One perceived advantage of HIV specialist social work was that there was less pressure on practitioners to close cases.

Geographical boundaries were raised as a particular issue. One participant pointed out the unfairness of the local specialist HIV social worker being able to provide excellent, intensive support to one young person, but nothing at all to another individual with similar needs living only streets away. The fact that health and social care services operate with different geographical boundaries can cause complications. Primary Care Trust boundaries do not always coincide with local authority boundaries; additionally there is a history in specialist HIV paediatric health services of treating children who live in a wide range of geographical locations, often quite far from the treatment centre.

One participant said that provision for safeguarding often prioritised children who are in need as a result of abuse or neglect rather than poverty, which could create obstacles for supporting young people in families with no recourse to public funds.

### ***The geographical distribution of services***

#### **Young people's perspectives**

Several young people reported feeling isolated by a lack of suitable health and voluntary sector services in their local area. For one young person, twice-yearly visits from a doctor based in another region provided the only opportunity to discuss HIV with a practitioner with specialist expertise.

Another person had moved to a new area at the age of 12, having previously attended a children's hospital, and was transferred directly into an adult service. S/he found it frightening, especially at first: 'They didn't know how to deal with me. They spoke to me like I was an adult but I was still only 12.' Although this transfer happened a number of years ago and the young person reported being well-settled now, s/he said, 'I wouldn't want another child to go through the same experience as I have.'

#### **Parents' and carers' perspectives**

The parents and carers consulted did not mention this as an issue for their particular families.

#### **Practitioners' perspectives**

Children and young people living with HIV in this country are a small population with some very specific needs. A sufficient number of service users are needed to develop a local service. However, practitioners identified real challenges for young people who do not live near services, including travel distances and transport costs if reimbursement is not available: one practitioner described a young person who had to miss a whole day off school and take three buses to each clinic appointment.

Conversely, practitioners noticed reluctance amongst some young people to use local services or inform them of their HIV status, because of fears around confidentiality or attachment to familiar services.

There was concern amongst practitioners about young people being unknown to any local health services, as this leaves them vulnerable in health emergencies where knowledge of their HIV status may be important for their care. It also makes it more difficult to keep in touch with those who become lost to follow-up, transition young people to services nearer their homes, and refer them to voluntary sector and social care services. Several practitioners described how young people had disappeared from care, then later presented very ill, requiring hospital admission.

One participant said that because data on young people living with HIV relates to treatment centres and details are necessarily restricted, it is difficult for voluntary organisations in areas without paediatric treatment centres to fund and develop appropriate services for an unknown number of local young people. Forming support groups can also be a challenge in areas of low prevalence: there may be significant gender imbalances or age differences within small groups.

Practitioners reported how challenges can arise in healthcare when paediatric and adult services are not in close proximity, whether they are on opposite sides of a town or several hours' journey away. Physical distance precludes a gradual handover of care with sufficient visits to ease the young person into the adult-focused environment.

The benefits and disadvantages of small and large treatment centres were explored. Having comprehensive teams including a range of professionals from different disciplines was seen as an advantage; on the other hand, the risk of over-involvement from 'too many professionals' was acknowledged. Young people using health and other services in areas of low prevalence might have access to more frequent and individualised support; on the other hand, transition arrangements may be less established and opportunities for peer support are more limited.

Practitioners noted that the population of families affected by HIV can be 'transient': the government has dispersed many asylum seeking families around the country, and people also move in and out of the country and join relatives in other areas. Young people leave home; some of those who go to university relocate their care and support whilst others choose not to. This can make it difficult to forge relationships, gauge progress and keep in touch with young people at a time when their lives are changing and ambivalence towards adults is natural.

**Practice examples: Being flexible about eligibility criteria and geographical boundaries**

One example of flexible service provision was an HIV specialist social worker who was able to work with anybody accessing care at a particular treatment centre, regardless of their area of residence. A few practitioners were able to work with people of any age. Some health practitioners could visit young people at home.

## Perceptions of transition and adult services

It was evident from discussions with all groups of people that young people living with HIV vary widely in their readiness and enthusiasm for taking ownership of managing their HIV and moving into adult-oriented services. Other events or circumstances may also destabilise or delay the process.

### *Awareness of changes*

#### **Young people's and young adults' perspectives**

In group consultations, young people were asked whether they felt they would need less support from professionals around living with HIV once they reached 19, or had needed less since turning 19. Generally, the response was 'no'. People recognised that they had already received a lot of information, but some felt they would need reminding or would require new information.

Young people varied widely in how they expressed understanding of the transition process. A few young people gave detailed explanations of how their engagement with health and voluntary sector services was likely to change, and understood their own role in the adjustment process:

*The way that they're saying it is that I should get my mind ready to be an adult.*

Others said they didn't know what would happen: one 17 year old thought that 'probably in my twenties or even older – then there I may see some big changes. [...] At the moment I have no idea how things are going change as I get older.'

In terms of health, some people were unsure about the roles of health practitioners working with them:

*I think he's just a paediatrician. I'm really not sure.*

This was sometimes the case for those who received shared care or attended family clinics which see adult and child patients at the same time. One person seemed to be seeing paediatric and adult doctors simultaneously without knowing why.

It is important to note that what might appear to be a hazy understanding of transition or of the distinction between children's and adult services is not necessarily a reflection on the information received or planning undertaken: young people may have forgotten discussions; changes in services may seem distant or less pressing than other matters; the job roles of those working with them may be of little interest; or their thoughts may not have been fully drawn out within these consultations.

Some young people appreciated the 'stepping stones' of transition:

*They're like starting me off slowly, [...] so it's like introducing me to my new doctor first [...] so when I go up I won't be too scared. [...] My next appointment, I'm meant to like look at the buildings and stuff so I know where I'm going.*

One young adult was aware that transition clinics are not a permanent alternative to entering adult care: 'I think I'll find it hard going from the [transition] clinic because I'm like really settled.'

Young people were generally quite clear about how they might engage with voluntary sector services in the middle-term. Continuing friendships with those met through peer support and the option of keeping in sporadic contact with familiar groups and practitioners were more important to most than having a new group to replace one they would eventually outgrow. Young people did not tend to imagine losing contact completely:

*I know if I really do need to speak still when I'm older, I know [my support organisation] and my doctor will still be there so I can still speak to them.*

### **Parents' and carers' perspectives**

Parents and carers did not identify young people's own knowledge of what to expect as a key issue: in general, the concern focused more on feeling in the dark themselves.

### **Practitioners' perspectives**

Practitioners reported starting conversations about the process of transition early, although acknowledging that the subject needed to be revisited periodically. The less formal and rigid the age boundaries set on services, the more organically this seemed to happen.

### **Practice examples: Mitigating anxiety around transition**

Beginning conversations about transition early and introducing young people to adult services and practitioners gradually, where possible, is considered good practice. Trying to ensure that, each time a young person attends a new service, they consistently see an individual with whom they can build a rapport would also address some of the issues raised by young people. Introducing young people to a peer already accessing an adult-focused service was another suggestion, as was joining new services in a pair if possible. Some clinics developed a transition plan with each young person, which the individual could keep at home.

Voluntary organisations have been involved in addressing anxiety around health transition through establishing a presence in clinic; inviting practitioners from adult services to support groups; and taking groups of young people to visit adult settings.

### **Adult environments**

The discussion with parents and carers did not cover this area in detail, focusing more on the role of family and practitioners, and their communication with each other, in supporting young people.

### **Young people's perspectives**

Settings were mentioned as an issue mostly in relation to health services, and generally paediatric settings were preferred to adult ones. One person said:

*It's all right, I guess, it's a bit gloomy but... It's not as fun as the children's one. Because children's is colourful and I get to colour and I get to go on a horse. [...] Just the whole thing of going to hospital anyway is bad enough as it is, but going to a place where everyone's just sat there, no one's smiling, it's in a grey hospital, everyone's like dead, like it's not nice.*

Two people accustomed to being seen in Children's Outpatients had concerns around anonymity in adult care. One mentioned feeling embarrassed going to the ID department in the lift, and the other said:

*At the children's, there was like parents and that who would say to hi to you [...] It wasn't mainly for people with HIV, I think it was like everything, like allergies. But now at the adults, it's just mainly infectious diseases. [...] In the children's, they didn't know you had HIV, but in there you kind of know.*

It was clear from the responses that clinic environments had a significant impact on young people's feelings about attending, and adjustment to, adult services. This point is important in light of concerns about loss to follow-up after transition to adult care.

### **Practitioners' perspectives**

Practitioners also considered environments important and generally mentioned them in relation to health settings, with young people seeming alienated by both 'childish' paediatric clinics and sexualised images of gay men in adult clinics.

Practitioners were aware that young people sometimes found adult clinics unfriendly. They also said it was important to ensure that reception staff were perceived as welcoming.

#### **Practice examples: Being creative about service environments**

One health practitioner offered patients the option to meet in a local café, attempting to create a more 'normal', relaxed interaction whilst carefully protecting confidentiality, and found that young people responded well to this. Several voluntary organisations have a presence within health settings, providing friendly faces, emotional support and, in one instance, food.

## ***Being amongst older adults***

### **Young people's and young adults' perspectives**

Young people were asked what they thought about encountering older adults living with HIV who may have had very different experiences of life and of HIV from their own. Some young people either had little or no experience of interacting with HIV positive adults outside the family. Those that did felt positive about it:

*They talk to me like I'm the same age as them. [...] They try and understand how, what's my side, like from having it from a young age and I try and understand how like maybe they just received the information, like they were free, they weren't positive the whole way through.*

*I think it's good because they're probably going to need the support more than I do because you know when you find out about something [...] you're shaken up for the first time. [...] I could probably help them in a way if they wanted and needed my help. I could help them and tell them how I coped with it and how it's not the end of the world.*

However, meeting older adults living with HIV is very different from receiving your own support alongside them, without other young people. Young people said that they might feel displaced, awkward and nervous around older adults, and noted differences in lifestyles and concerns. Some people in their twenties as well as teenagers expressed these reservations. One young person new to an adult service said:

*I've never seen someone the same age as me, never ever. [...] I end up going with my boyfriend because [...] they're all like older than me, I just feel like they're just looking at me like, 'What's she doing here?' I feel awkward.*

The presence of parents or carers in adult HIV support groups was not a commonly stated reason for young adults' reluctance to attend these groups.

### **Parents' and carers' perspectives**

One person said that his/her child 'doesn't feel that HIV has a huge impact' on life, and 'has lots of positive role models who are HIV positive around'. This sense of benefiting from parents' or carers' active involvement in HIV services or organisations was echoed by one young person. All groups consulted also referred to parents' and carers' own experiences of living with HIV as helping them to relate to what young people were going through.

## Practitioners' perspectives

Practitioners were aware of young people's discomfort. A couple of anecdotes from practitioners about young people striking up rapports with much older and very different people living with HIV are a reminder, though, not to assume how individuals will or will not relate.

As a group, practitioners were the most conscious of young people entering services already being accessed by parents or carers being a potential issue, particularly outside major urban centres. Practitioners relayed some of the feelings that young people had reported to them: these ranged from a strong antipathy to 'sharing' services to finding the presence of a parent or carer, or a degree of familiarity with the new service, reassuring.

## Developing independence and self-management skills

Young people were asked how in control they were of managing their HIV in various respects, and how this felt.

### *Getting the balance right*

#### Young people's and young adults' perspectives

Supportive relationships were what young people valued most highly and felt most lost without. Guidance and encouragement from parents and carers were central to many young people's experiences, as is clear in other sections. With regard to practitioners, young people often made reference to the importance of trust, respect and rapport:

*You know when you can trust someone and you know when they like believe in you or like listen to you properly? [...] They're like family. [My support worker is] like my sister. [My paediatric nurse is] like my other mum. [...] I feel so close to them. [...] I haven't known [my support worker] that long [...] but they're like family.*

*They treat me as a teenager: 'Girl, you're being naughty; girl, I see you, I'm watching you, I keep my eye on you' – stuff like that. They just treat me as a normal person. It's just that I go and see those people. If I was HIV-negative I wouldn't have those people in my life, so they're actually pretty helpful in a way.*

*I have a nurse who does my bloods and we have like a really friendly chat and she asks me all the questions like, 'Are you having safe sex?' So it's more her who I feel more down to earth with rather than the doctor who's really old and horrible.*



A relationship with a nurse appeared to be almost intertwined with one young person's identity:

*She's grown up with me. We've known each other since we were ten and stuff, so we've just got like that strong bond, like it's funny because I call her my auntie in a way. She's like part of my family, like, I couldn't imagine my life without her. [...] We've been together for like [...] eight years now.*

Letting go of a close bond by moving into adult services can be extremely difficult:

*I've rejected it! [...] I've had a lot of difficult years and you know, so, basically, it's a psychological thing. I don't want change and I don't want to move and I'm going to stay [...] until they actually kick me out. [...] My doctor has tried like in the past [...] He tried to make me transition. [...] I refused to have him as a doctor.*

On the other hand, developing independence, though sometimes intimidating, was generally described in positive terms:

*At first it was a bit worrying but [...] it showed me that I was growing up, [...] I was the person in charge of [my own health] because doctors can give advice and stuff but ultimately I was the decision-maker. So I guess it kind of showed that I was mature and things like that, so that was quite cool.*

In group consultations, young people were asked whether they felt they needed to talk about how HIV affects their life with a worker from outside their clinic. The majority said yes, with some people not minding and others feeling that 'both of them give me support' in different ways. One person said, 'It's nice to talk to someone in between. [...] I don't feel like just a patient.' Some people encountered a practitioner from the voluntary sector within their clinic environment.

Relationships that previously felt comfortable might become less so as a person develops. One girl's comment that her 'male doctor makes me a bit uncomfortable now I'm 13' reminds us to consider that the personal characteristics of practitioners may be important to young people. Whilst it cannot tell us much about the proportions of men and women working in different roles across the sector, it is perhaps interesting to note that five out of six focus group participants were women.

Tentativeness towards, and difficulties connecting with, adult practitioners were unfortunately quite common. Several people in adult care reported feeling scared of the doctors, or resenting what they felt was a failure to engage or get to know them due to eagerness to 'get stuff done quickly'. Two people had seen a number of different doctors. One person said:

*Sometimes I feel like not going. [...] I hate hospital. [In the adult clinic] I've had three appointments; I've had three different doctors. I just want one doctor like I had. I felt I knew him personally. He talked to me, just had a conversation with me, like, how was school and that. I mean, they do, they say, 'How's work?' and that but [...] I need that attachment thing so I can be able to like say, talk about anything. I don't feel like when they ask me about my sexual health, I feel like, 'Uh, I don't know if I should talk to you.' [...] They feel like them kind of people you're scared of. I just look at them and think I should keep back a bit [...] I'm not saying they're not [approachable]. They're just... I don't know. I need to have one doctor and he needs to get to know me, know what's happening in my life, not just bits of what's happening in my life, but know me personally.*

This is in contrast to this person's experience of the paediatric service where the nurse 'was there all the time, all the time'.

However, one young person who entered HIV care in adolescence was highly satisfied with having been offered the choice between attending the paediatric and adult clinic. S/he chose to go to the adult clinic: 'I've always gone to adults and they're nice there, they always ask me about school and remembered about my exams.'

Familiarity was important across the board. Young people in group consultations, when asked whether they liked their doctor or nurse to talk to them about how HIV affects their life outside the clinic, generally said yes: 'I like the personal approach' and 'It's better to talk aloud.'

#### **Practice examples: Offering choices to young people**

One example from health is showing young people GUM and Infectious Diseases departments to see which they prefer. Another is to allow individuals to choose from a number of appropriate people to input into planning and supporting their transition.

#### **Parents' and carers' perspectives**

Parents and carers emphasised the importance of practitioners listening to and ascertaining the wishes of young people around negotiating independence and the involvement of parents and carers. They also thought that listening to parents and carers could help practitioners understand a young person's needs better, saying: 'We live with our children; we know them.' They urged practitioners: 'Don't tell us what to do. Teach us.' They said practitioners should 'get to know the patient and the family'.

One person felt that, in his/her experience, concerns around independence and children's rights had been seen by health practitioners as conflicting with a respect for family values and working with the family. There was discussion around being labelled 'difficult' or 'worried' and how not helping families to understand the care being given can lead to young people missing out on well-coordinated emotional support:

*If they are working with the family, it helps. [The young person] would have coped much better had this taken place.*

Another person said that the healthcare team 'always worked with family'. The consultant would arrive at work early so that the young person's appointment didn't result in missing school. A voluntary organisation was identified as having worked well with the whole family.

A parent/carer described a young adult who managed living with HIV very competently and linked this to strong relationships.

#### **Practice examples: Supporting parents and carers**

Meeting the needs of parents and carers is a broad area encompassing wider support for families as well as services for adults living with HIV. A number of voluntary organisations run groups or courses for parents and carers, which may address topics such as communicating with adolescents and communicating with health professionals. One health practitioner described offering parents or carers an appointment of their own to discuss transition, and allowing them to look around the adolescent clinic.

#### **Practitioners' perspectives**

Practitioners explained practical factors that perhaps explain what some young people may perceive as a failure to meet specific needs or provide services that take into account their routines, pressures and interests. Adult HIV treatment centres have much higher numbers of patients than their paediatric equivalents. Naturally, practitioners in adult-focused services cannot offer the level of proactive, intensive support that their counterparts in children's services are also stretched to provide. A couple of cases were described where transition in health settings was 'backtracked' because young people were struggling so much in adult services.

One practitioner in a GUM clinic which received a newly diagnosed patient said, 'We did everything so he could still follow up his dream [...] and still be a 17 year old kid.' However, this was only possible because the patient was a single 'special case'; it also helped that the practitioner had a lot of experience of working with adolescents.

Voluntary sector HIV services were praised for providing holistic support that addresses their clients' concerns beyond HIV – for example, careers advice. However, the need for young people to be able to access and engage with services and opportunities outside of HIV organisations was also highlighted by practitioners, including those in the voluntary sector.

Differences between young people with HIV diagnosed at birth or in infancy, young people with vertically acquired HIV diagnosed more recently, and horizontally infected young people, were explored. Overall, no group was described as clearly more or less self-reliant or mature than another: it was highly individualised. Being 'protected' by family and services was, however, noted as a feature of growing up with HIV for many young people, and the physical and mental health of parents and carers was also identified as influencing the ease with which young people develop independence,

particularly for young carers. Practitioners' references to parents' and carers' protectiveness described a huge diversity in responsiveness to children's needs and wishes; and acceptance and expectations of children's autonomy.

It was a concern that newly diagnosed young people, particularly those with horizontally acquired HIV, tend to enter directly into adult healthcare and may miss out on the intensive support which is more readily available to paediatric patients. The particular devastation of receiving an HIV diagnosis as a pregnant young woman was also acknowledged. Horizontally infected young people might rely heavily on health practitioners if family members are not informed of their diagnosis. One adults' health practitioner said of a newly diagnosed patient who 'didn't want Mum or anybody to know': 'I was his mum, basically [...] I was replacing her because he couldn't tell her.'

Practitioners working in paediatric and adult health services discussed the advantages and disadvantages of their own varying degrees of protectiveness and intensive input, describing difficulties in maintaining a firm but gentle shift towards independence for young people. One participant said that the HIV sector in general is protective: the reasons for protectiveness are understandable but an awareness of it can help avoid over-dependency or unsustainable support. A paediatric health practitioner mentioned that feelings of protectiveness were heightened if young people did not have strong relationships with parents or carers; levels of confidence in colleagues in the adult service also influenced willingness to 'let go'. Some practitioners will have known young people since infancy, and several women talked about being referred to as 'auntie' by some African families, reflecting the attachments to relationships formed with health practitioners by both children and adults in families.

Descriptions of relationships between adult health practitioners and young people varied. Some with experience in or a natural aptitude for communicating with young people managed to strike the ideal balance between responding to patients' youth and treating them like adults; others who had more limited learning opportunities or less confidence or interest in working with young people struggled to develop rapport. It was pointed out that working with young people is not uncharted territory for practitioners based in GUM clinics, which frequently see young people and communicate with them about sensitive issues. One person highlighted how important it is that young people feel able to feed back to at least one member of a professional team on how others are working with them.

Some voluntary sector practitioners referred to disengagement from their services resulting from a genuine absence of need being a positive outcome for young adults, and described a range of services designed to promote and sustain confidence, resilience and the development of life skills. Issues may arise for young adults with chaotic lives or complex challenges who want and need peer support, given the tendency for older members to engage through taking on active leadership roles, which may not be possible for everyone. Otherwise, voluntary sector practitioners spoke positively about young adults acting as role models.

### Practice example: Adapting ways of working and communicating for young people

One example of 'young people friendly' communication is using mobile phones – texting, in particular, helps many young people to keep in touch. One practitioner said: 'You can only give them information that can be programmed into a mobile phone in code [...] If you vomit, ring this number!' Asking individuals to fill out contact details forms regularly can avoid them disappearing if they change or lose their mobile phone.

### *Clinic appointments*

#### Young people's and young adults' perspectives

Most young people said they had the opportunity to make decisions about their own HIV care, in terms of appointment times, going into appointments alone or with somebody else, and moving into adult care. One person highlighted the contradiction of being expected to attend appointments by an HIV positive parent who did not engage well with care themselves.

It was not unusual for the young people interviewed to be accompanied to clinics by parents or carers, but all said that either nobody came into the actual appointments with them, or they had opportunities to speak to health practitioners alone:

*If [my mum] wasn't available to go with me, I would definitely go by myself [...] [If] I want to talk to my doctor, sometimes she will wait outside. But when it's just normal stuff, you know, just having more medicines and the blood testing, she'll come in.*

*I'm an independent person, I hated it when my mum came hospital with me and I hated my mum telling me to take my meds, and I hated all that. [...] I was like, 'Basically, I don't want you guys telling me what to do.' [...] You know, I'm 17, I'm not 10. I can do all this by myself.*

One young adult said:

*If it wasn't for [my doctor], [...] it wouldn't surprise me if my mum would like still be coming to the appointments with me. Not because she's necessarily [...] controlling but just because that was our routine when I was in the children's one, so it would be hard to break the routine. But I think what [my doctor] did was [...] she gave me more control like over my status because before I guess I'd be in the same room as my mum talking to [...] the paediatrician, and then I would have to leave. [...] But now it was kind of the other way round. I was, like, in charge of it, and then my mum would find out everything because I was the one that told her.*

Two young people mentioned the logistics of getting to clinic independently. Challenges were travelling to a clinic far from home, and missing school.

### Parents' and carers' perspectives

Parents and carers recognised young people's need for greater privacy but discussed how 'whatever happens in the clinic or group, the children still always come back to the same parent' who is with them in between appointments and meetings, and a feeling was expressed that the central role of the family could be better appreciated. Comments were made about the principle of working with families being 'good on paper' but not always realised in practice.

### Practitioners' perspectives

Practitioners were aware of the issues above. They talked about the importance of parents and carers in supporting young people and providing a link in cases where young people disengage from health services, and how this sometimes conflicts with young people's needs for, and rights to, confidentiality.

#### Practice example: Clinic appointments

Several health practitioners mentioned that it worked well to see a young person alone for the first part of an appointment, then invite the parent or carer in.

Practitioners also mentioned one way of working with young people who do not attend clinic. A 'contract' or agreement between the healthcare team and the young person sets out the circumstances and ways in which the team would contact a parent/carer or other appropriate adult chosen by the young person.

### Managing medication

#### Young people's and young adults' perspectives

Some young people had never taken treatment; some had since childhood; others had taken treatment previously in childhood but had stopped for several years prior to starting again. Most people interviewed managed their treatment independently. One person talked about the importance of coming to terms with the need for medication:

*That's life. Taking responsibility for the things that you do and knowing that there's a consequence for whatever you're doing. [...] The thing with HIV is you're not going to get sick straight away so you can feel fine tomorrow and feel fine the next week, and feel fine for a couple of months down, even years, but then one day you will be sick. [...] The constant reminder that you actually need it in your life is like saying that you wake up in the morning and you brush your teeth, don't you? Everybody does. Everybody – that's their routine in the morning. My routine in the evening: I brush my teeth, I take my medicine and I go to bed. That's how it works. It's just a system now. So I think it's going really well.*

Another young person talked about the difficulties of coming to terms with taking medication, and how a voluntary organisation helped through one-to-one support around HIV as well as an open youth group:

*I would keep telling myself that [...] I'm going to have to take medicines for the rest of my life. [...] Things went bad for me. [...] I didn't want to talk to nobody, I still had that problem of being scared. I feel like I was like in a box and I was all alone, and I didn't feel like anybody was helping me. [...] And the way [the organisation] helped me was [...] I didn't have time to be, you know, to be scared or to be, you know, to be in the dark, to be trapped. [...] I didn't feel comfortable talking about the things I had, they just helped me by, you know, keeping me busy.*

Practical tips and tools were appreciated, and young people identified calendars, pill boxes, phone alarms, text reminders, one-pill a day regimens and 'keeping the medicine in my room' as useful.

One person who struggled with managing medication and was due to move to an adult clinic in the near future, said:

*I mostly have to be reminded to take my medicine otherwise I just won't even remember at all, it completely like goes out of my mind. And my appointments – [...] my social worker usually knows and she'll like remind me. [...] I think I'll probably get a shock when I move or something.*

### **Parents' and carers' perspectives**

Adherence was described as 'a huge problem' for one young adult; reminders of 'the visible effects of not taking medication sometimes help'. One parent/carer felt that for his/her child, a young adult, not being on treatment made it 'easier not to think about HIV'.

Parents and carers also emphasised the importance of taking into account the full range of factors affecting young people's adherence and wider health and well-being.

### **Practitioners' perspectives**

Practitioners described variable treatment experiences: young people who maintain excellent adherence to treatment and find its interference in their lives is minimal, those with patchy adherence who struggled more with motivation, and those who refused treatment altogether including a small number of young people who had died. Some young people's adherence seemed strongly influenced by parents' or carers' own adherence.

Practitioners were not surprised that sticking to a strict regime of drugs which have unpleasant side effects to treat a condition which may not be causing any symptoms in the short term is a deeply unappealing prospect for many young people. Common features of adolescent and young adult life, such as irregular sleep patterns and binge drinking, can also jeopardise adherence. Practitioners reported finding it hard to help young people

balance their natural and right desire to lead ordinary, enjoyable lives with a recognition of the need to look after their health, including managing diet, fitness and stress. Voluntary organisations were repeatedly noted to be an important source of support, as were the practical tools mentioned by young people. In serious cases, directly observed therapy and gastrostomy tubes into the stomach are used.

One person highlighted that, whilst practitioners are aware of the dangerous consequences of poor adherence to treatment, focusing on this too intensely can drive young people away:

*Expecting everyone to have 90 per cent adherence and an undetectable viral load is like pushing everybody to get 3 As at A level. The grounding expectation should be to be in touch with the young person, so they know they can come back to you.*

One practitioner pointed out that guidelines on medicines differ for children and adults due to licensing and funding arrangements. If young people are as medically stable as possible prior to transition, it helps with HIV treatment planning, not least because assistance available around adherence will be significantly less intensive in adult services than in paediatric services.

### **Disclosing HIV to friends and partners**

#### **Young people's and young adults' perspectives**

Young people's participation in support services or consultation for this project indicates that they have 'permission' to share their status. Most of the young people interviewed talked about decisions around disclosure to friends or partners as their own decisions to make.

*Ever since I knew, I was given a choice by my mother. She'd say, [...] 'You know who you trust and you know who you don't trust. So if you feel comfortable telling somebody because, sometimes it's easier to tell someone. [...] You can talk about, you know, private things that you wouldn't normally talk to some other people like other adults.'*

Generally, people did not want or feel the need to disclose to many people, particularly if they found support around living with HIV elsewhere:

*I have done it. I've found it difficult. [...] I have told some people, who I thought I would never tell and I thought they would have reacted badly but it hasn't. [...] I feel like [my friends] already do know [...] something's up but I haven't felt the need to tell them.*

One young adult explained how having an HIV positive partner had removed the pressure of disclosure when she was younger:

*It was kind of like very easy, that relationship. [...] Even when we weren't even official, I could take medicine in front of him and stuff like that, and there were no questions and he could even come with me to the clinic.*



Some young people wanted advice on disclosure but also tips on how to protect their own confidentiality whilst developing independence, e.g. coping with nausea and having a story to tell if seen with medication at sleepovers.

Two people did say that parents resisted them choosing to tell friends, with one feeling forbidden from accessing peer support:

*Mum pressures me not to tell anyone but she has support about her HIV so it's not fair, whereas I don't have anyone but I need someone, and can't always talk to Mum as there is an age gap.*

The young adults varied widely in their experience of disclosing their HIV status to people in their lives. Some people didn't tell anybody: 'That secret life, I don't like it but it works for me.'

One woman said she'd told a few select, long-term friends: 'My friends were the ones saying, "Don't touch him, he's got HIV." I had to educate them.'

Another young woman has gone public and appeared in the media: 'I was tired of hiding my true self. I missed myself.'

#### **Parents' and carers' perspectives**

Within this group, comments were made about explaining to young people that disclosure of HIV information is 'up to [them]' and outlining 'the pros and cons'.

#### **Practitioners' perspectives**

The experiences reported by young people above were familiar to practitioners, who were keen to help with managing this. Some said that it is not uncommon for young people, when HIV is named to them, to be told not to disclose to anybody.

Disclosures that happen suddenly due to condom breakages and the need for partners to take post-exposure prophylaxis to avoid infection were identified as particularly difficult. Negotiating safer sex was mentioned in the context of heterosexual relationships, with power dynamics and dependency on male partners to use condoms creating difficulties for some women, and some men struggling to persuade female partners who use other methods of contraception that condoms are necessary. Practitioners were aware of the range of reactions young people experienced upon disclosing their status to friends and partners, from violence to impressive degrees of empathy, considering the widespread misinformation and stigma around HIV. Aside from addressing the issue in the normal course of service provision, some practitioners invited young people's partners to contact or visit them to learn about HIV, or to attend services as a couple. They recognised potential benefits for young people living with HIV of forming intimate relationships with each other, but felt it was important that they didn't see this as their only option.

## Transition and the family

HIV can impact on family relationships in complex ways, and family circumstances can interact with all aspects of transition. Changes in family dynamics will also be happening alongside young people's transitions between services, as part of the normal processes of adolescence. The role of family is threaded throughout the consultation findings. This section focuses specifically the impacts of an HIV positive young person's growing up on others in the family.

### Young people's and young adults' perspectives

This comment offers some insight into how growing up with HIV can impact on wider family dynamics: 'I feel weird that none of my brothers and sisters have HIV and I do, a bit "Why me?" But then I think the only thing that's different for me is that I go to clinic and take medicines.'

One person made a poignant comment which showed how, in early adulthood, young people may begin to relate to HIV positive parents in a new way: 'The only time you're happy is when you're alone. I used to ask my mum, "Why are you always on your own?" and now I understand.'

### Parents' and carers' perspectives

There were some tensions reflected by parents and carers between themselves and health practitioners during transition, with some members of the group feeling criticised or disapproved of by practitioners. One person felt that it had been implied that her family were 'overdoing the Christian thing'. Several people acknowledged that at times it felt to them like a 'conspiracy' against parents and carers. They also felt that this tension sometimes affected relationships between parents or carers and their young people.

There was also a feeling that help was slipping away as young people got older and that families were left to deal with this: 'I felt so helpless'. One parent/carer described how waiting for appropriate support for a young person and avoiding 'information being passed around' during multiple referrals between professionals had led to 'investing personal money [in private services] to maintain wellness'.

Several people identified siblings of young people living with HIV as playing an active role in providing support.

One member of the group described a young person who 'doesn't like being around other positive people', including family members. Another attitude described was, "'You gave me this, you deal with it.'" These feelings, or the perception of these feelings in young people, will have an impact on family relationships.

A suggestion was made that it would be useful to have 'a confidential network for parents', and it was felt that a web-based resource might work.

## Practitioners' perspectives

Practitioners working in health raised the issue that the transition of young people into adult care can have a direct impact on the care of HIV positive parents. An adult can only access HIV care at a family clinic on the basis that he or she has a child in paediatric care. If this ceases to be the case, the adult also makes a transition of his or her own out of the family clinic.

One practitioner mentioned that some young people, as they get older, begin to bring HIV-affected siblings to clinic with them as support, and that in these cases, it is important that professionals are mindful of the sibling's awareness and understanding of HIV in the family. Some affected young people are not told about HIV in the family at all, or not until adulthood.

Several practitioners emphasised the need to remember that young people who are affected by HIV but not HIV positive themselves may go through transitions of their own in terms of understanding HIV and how it affects them and their loved ones, and entering adulthood. HIV-affected young people are harder to identify and often have poorer access to information and professional input than their HIV-infected peers. Affected young people may receive support from voluntary sector and statutory social care services.

Practitioners noted a high proportion of young carers in families affected by HIV and discussed how, when young people who are living with or affected by HIV take on caring responsibilities, this impacts on their experience of adolescence and young adulthood. Their needs to develop independence are likely to have consequences for the whole family.

### **Practice examples: Promoting positive relationships between young people and their families**

Several organisations offer whole-family activities such as day trips and even residential to facilitate families spending quality time together. Involving young people in delivering sessions for parents and carers, presenting their concerns and ideas, is another approach sometimes used.

## Health and well-being

A young person's state of health, or concerns about health, may affect and be affected by the smoothness of their transition. Issues around adherence to treatment are discussed in 'Managing medication' above.

### **Young people's and young adults' perspectives**

One young person interviewed emphasised that healthcare should not focus on physical health and treatment at the expense of everything else:

*It's not just about your body. [...] Sometimes it's really difficult as a young person to go clinic, yeah, have the same conversation with your doctor: 'Take your medicine.' OK. But you've got something else on your mind [...] like your friend's just died or something like that.*

Young people in one group consultation felt that 16 year olds needed a 24-hour helpline for when they were feeling depressed and alone as well as help with managing stress.

One comment from a young adult showed how living with stigma can affect mental well-being. She experienced paranoia:

*I've heard there are some signs that you can tell someone's got HIV. You'd have to have read all the medical stuff, but... [I think] 'This woman's looking at me.' [...] I'm a black girl going into a sexual health clinic.*

Several young adults – but none of the younger people – reported experiencing sleeping problems, or at least difficulties relaxing, and associated these with HIV. One person contrasted the confidence and acceptance she'd shown by openly discussing her status with the fact that 'I haven't slept since I was diagnosed. [...] It's like I'm locked. [...] I didn't want to sleep because I thought I was going to die.'

One young adult spoke about suicide: 'You contemplate suicide. I know I have but now I don't because I want to go places in my life.'

The young adults consulted talked about 'acceptance as the breaking point of understanding your status' and also mentioned 'not letting it define you' but their wider responses seemed to suggest that for some people, these concepts may be acknowledged but not fully felt. Comments were made about the challenges of acceptance:

*I don't think I'm normal to be honest. It's messing up my life structure.*

The way the young adults spoke about acceptance suggested that, for them, acceptance of HIV is not a linear journey, but more of a 'Snakes and Ladders' experience, with new processes of acceptance needed in response to changing phases in life. This is natural, but highlights that young adults have their own needs for support to reconcile themselves with living with HIV in light of new experiences and concerns.

### **Parents' and carers' perspectives**

Identity, mental health, sexuality and social well-being were discussed. Anxiety and fatigue and were also identified as issues for both young people and their parents and carers.

There was some mention of difficulties with social interaction, described in terms of fear of socialising and some antagonistic behaviour. These were seen as protective strategies to avoid potential rejections. However, some young people were described as having much healthier social relationships, but it was pointed out that perceptions of 'problems' should be seen in the context of young adulthood in general and not just HIV:

*She is also doing what others her age are doing. In terms of relationships, she has not been in a proper relationship but I'm not too worried because her peers, who are not positive, are also single. She feels she has more going for her than HIV.*

### **Practitioners' perspectives**

There was universal agreement that attempts to address medical needs without considering psychosocial needs are doomed to failure, and that the complex range of potential psychological stressors on this group of young people is a challenge for services.

Practitioners discussed the difficulty of being a young person surrounded by pressure from peers, the media and advertising to meet certain physical ideals, and how HIV aggravates this experience. Vertically acquired HIV is associated with delayed puberty and small stature which can undermine body image, and some side effects from antiretroviral drugs can be extremely distressing, e.g. weight gain and symptoms of lipodystrophy such as breast fat accumulation in young men. Side effects such as fatigue can interfere with functioning, social interaction, and engagement with services.

Another issue raised was the difficulty of giving young people with vertically acquired HIV answers about their long-term outlook and life expectancy, given that young adults with vertically acquired HIV are a relatively new phenomenon. According to practitioners, young people vary from planning for futures in which HIV is almost an afterthought to worrying intensely about AIDS and death.

The high incidence of mental health difficulties amongst this group of young people was discussed extensively. It was felt that the long-term experience of growing up with diagnosed HIV and the experience of being diagnosed in adolescence could each create huge psychological strain. Practitioners also identified additional stresses they were aware of in some HIV positive young people's lives, ranging from socioeconomic disadvantage and discrimination through to sexual abuse, assault or exploitation. Poor health and death of parents and other family members were cited as common issues for young people with vertically acquired HIV. Also, many young people have either moved to the UK from abroad or been born here to foreign-born parents, so circumstances leading to, and experiences of, migration may have first- or second-hand effects on young people.

Young people lacking access to clinical psychologists with the required specialist training and experience was raised as an issue in several areas. One practitioner in a centre where psychology input was available mentioned that uptake was poor, probably due to the stigma attached to needing psychological support. Other health practitioners, particularly paediatric Clinical Nurse Specialists, report that providing psychological and social support constitutes a large proportion of their workload, but health services have limited capacity or remit to address some of the areas in which young people need assistance and advocacy. This is an issue particularly when young people are without access to, or choose not to engage with, voluntary sector services or statutory social care, which

provides much of this assistance and also offers an alternative environment and relationship dynamic. It is also significant in that young people who have become used to accessing broad psychosocial support from nurses in paediatric healthcare are likely to feel an impact of that loss when the same breadth of service from adult nurses is either not possible or usual.

Several practitioners mentioned young men talking less openly about personal matters than young women, and engaging less with psychosocial support.

One concern relating to physical health was the difficulty of getting young people approaching 18 admitted in children's services if they need inpatient care.

**Practice examples: Enabling isolated young people to access psychosocial support from the voluntary sector**

In recent years, access to support for young people who are not involved with regular groups due to geographical isolation or personal choice has improved. In addition to individual face-to-face work, increased availability of residential, online and long-distance support, occasional visits to groups in other regions, and one-to-one peer mentoring allows young people a range of ways to engage.

Many services make efforts to reach isolated young people. One example is Children with AIDS Charity (CWAC). The main focus of the organisation's direct work with young people living with HIV is on supporting young people who might find it difficult to engage with other services for various reasons, including crime and drug misuse.

## Professional approaches

### *Collaboration*

#### Young people's perspectives

Young people did not tend to see their experiences in terms of how practitioners collaborated for their benefit. One person did make a comment which shows how important it is to find out from the young person what information sharing is helpful for them and what is not:

*[My paediatric nurse] was like [...] 'I'll introduce you to everyone and tell them about you then I'll tell them what you're like and all that.' Say, my stepmum, we don't get on, so she was saying she was going to tell them to make my appointments different days to my stepmum.*

Another young person's description of potentially having missed out on an opportunity to benefit from peer support earlier highlighted the importance of practitioners working jointly:

*I had absolutely no idea that there was any sort of group in [my region] until I went to [...] the conference and then I met one of the ladies who runs a group [...] So I'm going to start going there I think.*

### **Parents' and carers' perspectives**

One parent/carer felt there was a lack of collaboration and coordination between services: 'Agencies involved with us operate as individuals.'

### **Practitioners' perspectives**

Forging links between people and across services proved difficult for practitioners in numerous respects. Services aimed at children and adults have contrasting cultures, as do health, social care and voluntary sector services: relationships can become strained even when there is goodwill. Managing the sharing of information across services was identified as a challenge. Practitioners emphasised the importance of having named contacts in other services.

Physical distance makes collaboration harder – an issue raised particularly by health practitioners working outside London and in relation to young people moving to new areas. The configuration of services and clinic times can also prove problematic. In addition, some paediatric treatment centres have more than one key centre receiving transition patients, multiplying the relationship-building, communication and practical coordination required. Differences in practitioners' working patterns can make collaboration difficult within and across services.

One practitioner mentioned that as young people enter adulthood, those who are highly engaged with the HIV sector become aware of elements of it that can be hard to understand or accept, such as the implications of services and organisations needing to compete for funding.

### **Practice examples: Making use of other practitioners' experience and tools**

Facilitating opportunities for networking, practice-sharing and the dissemination of information and resources is a key function of the Children and Young People HIV Network. A number of other networks and associations also link practitioners for specific purposes, including CHIVA, the HIV in Young People Network (HYPNet), the UK Family Project Forum and region- and discipline-specific practitioners networks.

### ***Awareness and attitudes***

#### **Young people's and young adults' perspectives**

Young people's comments on awareness and attitudes mainly focused on school. Telling schools about a young person's HIV diagnosis is difficult and mostly avoided due to stigma. Young people living with HIV, and those who support them, expressed concern at schools' ability to handle HIV appropriately. Several young people in interviews or group consultations mentioned schools reacting badly to disclosure of their HIV status, and sharing this information without seeking permission.

When asked whether they would like their school, college or university to know their HIV status, young people in group consultations almost unanimously said no. Any potential benefit was greatly outweighed by the potential cost of telling:

*I don't see how my HIV affects how I'm doing at school. What's it got to do with it?*

*Teachers are still people and judgmental, they've not got information about health, so telling them is a big risk as I don't know how they'll deal with it.*

On the other hand, the positive attitude taken by a university students' union had had a strong impact on one person's feelings about how others perceived HIV:

*Even though they don't know about my status, they were very supportive when I told them that I thought that the university, i.e. the union, should have more awareness surrounding World AIDS Day.*

### **Parents' and carers' perspectives**

Within this small group of parents and carers, there was some expression of discontent with some of the approaches taken by specialist HIV practitioners in health settings. Whilst some were considered 'very sympathetic', others were felt to be 'complacent' and 'patronising'. Feelings about social workers were similarly variable, with some considered very sensitive and helpful, and others criticised.

Another comment related to a young person being referred to a psychologist for appointments with which s/he did not engage, whilst the emotional support provided by the family was felt to be under-recognised: 'As much as a child says they don't want your help, they probably do, even indirectly.' It was noted that family may be taken for granted.

One comment was made about respecting the dignity of parents and carers in terms of the need sometimes to 'detach you from negative aspects of your life story and your low points' in order to communicate effectively: 'I'm not a victim of my circumstances constantly.'

One person said of a young adult who struggled to accept her HIV status but 'does well at education': 'It's as if she's chosen to study [a particular subject] in search for answers.' If this is the case, it suggests that some young people use education as a way of making sense of living with HIV, making positive experiences of being a pupil or student all the more important.

### **Practitioners' perspectives**

In terms of parents and carers, practitioners talked about the need to understand, respect and work with different cultural conceptions, for example relating to childhood, family relationships, gender and sex, and



community. Confidence in their cultural competence appeared to be changeable, but awareness and respectful intentions were widely expressed.

In terms of other practitioners, there was much discussion of how the poor HIV awareness common amongst the public is reflected in the public services workforce, as their opportunities to gain and refresh HIV knowledge and explore HIV-related stigma may be limited or non-existent in work contexts. Participants from all sectors expressed frustration around working with professionals of all kinds who had little knowledge or experience of HIV, or who felt that HIV services should be able to meet all the needs of people living with HIV. It could be a struggle to harness resources, negotiate access to appropriate support, agree responsibilities, ensure confidentiality, prevent 'knee-jerk' reactions and encourage positive relationships between young people and those involved in their lives. One voluntary sector practitioner spoke of how difficult it was to 'get into' schools to do HIV education work.

Aside from public sector employees in general, the other key group with which participants felt positive communication was particularly important was faith leaders. Practitioners recognised the importance of faith to many young people, in providing hope, guidance and community for individuals; either tackling or fostering HIV-related stigma; and helping with or undermining adherence to treatment.

### ***Capacity and skills***

Practitioners talked a lot about their own capacity to provide the best possible services.

### **Practitioners' perspectives**

Working with 'a slow drip' of young people moving into adult services – in some cases, one individual over the course of several years – makes it extremely difficult to mobilise resources and develop skills to support this process. Some adult health services were seen as hesitant to receive transitioning patients, either because of concerns around working with young people or because of an awareness of the input and resources needed to effectively meet their needs. For example, evening clinics are often most convenient for young people, but offering this is not always a possibility and, where it is, has a significant impact on staff.

Confidence was identified as an issue: both practitioners' confidence in themselves and in each other, across children's and adult services, disciplines and sectors, and geographical divides. One practitioner working outside London felt that the HIV sector could sometimes be 'London-centric', failing to recognise that the quality of care and support in other areas could live up to, and in some cases surpass, that available in the capital.

Concerns around continuously developing and sustaining support for young people were raised. 'Success stories' usually involved individual practitioners with exceptional levels of interest, commitment and skill going

beyond the call of duty and often working way beyond their paid hours. Reliance upon this is not a fair or secure way of ensuring needs are met.

The first case study below reflects many of the challenges for health services examined in this report. The second, over the page, presents a radically different situation and illustrates how services with comparatively large capacity face some similar challenges to smaller services, and some different ones.

#### **An adult health service in an area of low paediatric HIV prevalence**

Chris\* is an HIV Clinical Nurse Specialist working in a hospital GUM clinic. The few children living with HIV in the local area are usually seen in Children's Outpatients by a Consultant Paediatrician several miles away. The regional lead centre for paediatric HIV care is some distance away.

Chris's clinic began supporting its first transitioning patient in 2010, and within six months, had received four further young people in their teens. All but one of these individuals had been newly diagnosed despite all having lived with long-term or lifelong HIV infection. All but one entered paediatric care initially. A small number of younger adolescents are likely to transition into the GUM clinic in the future.

Chris and her team have, therefore, had to begin their work with transitioning young people suddenly, and their lack of opportunity to develop experience over time in this area hampers their confidence. Making the GUM clinic environment inviting for the young people is also a challenge. Chris wants to set up a family clinic but faces concerns of others around health and safety, the impact of making the environment 'child-friendly' on established adult-focused ways of working, and awareness of differences between taking blood from children and adults.

Chris's service has been working with a local voluntary organisation to set up a peer support group, which is beginning to take shape. A Paediatric HIV Clinical Nurse Specialist post covering Chris's area and a nearby city was filled in 2011.

The case of Chris's service demonstrates the difficulty of developing and sustaining age-appropriate services for small numbers of HIV positive young people, along with the commitment of individual practitioners to making transition work. It also highlights the importance of testing the children of parents with diagnosed HIV, as well as remembering that there will always be some individuals entering adult care who were either not infected or not living in the UK as infants and therefore not diagnosable, or who were not fully engaged with paediatric services for other reasons.

\* name has been changed

**Imperial College Healthcare NHS Trust – the 900 Clinic**

The 900 Clinic at St Mary's Hospital in London provides services for about 80 young people aged 16–25, primarily with vertically acquired HIV, many of whom have previously accessed paediatric care at St Mary's. The clinic was set up in 2006 and includes doctors specialising in adolescent and adult health, a psychologist, a dietician and specialist nurses. The clinic and its staff also play an important role in research into HIV in adolescents.

The 900 Clinic aims to provide 'one-stop shop' care including HIV care, sexual health and contraception services, vaccinations such as hepatitis A and B, and counselling and post-exposure prophylaxis for sexual partners. The clinic offers afternoon appointments and a weekly drop-in service, as well as text and email contact. It also has links with voluntary sector services and a dedicated peer support worker from Positively UK.

What, then, are the challenges for a clinic that provides services many practitioners in other areas would love to be able to offer?

Firstly, the 900 Clinic cannot make the complexities of growing up with HIV go away: some young people get through adolescence with extraordinary ease, but others will struggle no matter how extensive the support.

Secondly, services such as the 900 Clinic, like all HIV services, may be affected by the changing landscape of healthcare. The exact changes and their impacts are not fully apparent at the time of writing.

Thirdly, it is important that all young people, irrespective of transmission route, have equitable access to services. Higher loss to follow-up rates have been noticed amongst horizontally infected young adults than those with vertically acquired HIV, and therefore these young adults need to be engaged in services and healthcare in ways that meet their specific needs.

There may also be an unintended consequence for young people of fully engaging with youth-focused services, especially those that are involved in or leading sector-wide development work, and that have a substantial 'pool' of potential research or consultation participants. Young people may begin to feel over-researched. On the other hand, there are still significant gaps in our understanding of these young people. In particular, there is as yet no evidence of long-term outcomes in the fourth decade of life.<sup>6</sup>

Involvement in a smaller service may offer young people more individualised personal care, although the same key principle of facilitating transition by close and integrated paediatric and adult services with an identified lead for transition applies to services of all sizes and settings.

Finally, health facilities, including the best-equipped, are unable to meet the needs of young people who are affected by HIV but not themselves infected with HIV, who greatly outnumber their HIV positive siblings and peers.

---

<sup>6</sup> An Adolescents and Adults Living with Perinatal HIV (AALPHI) study has been set up to investigate the impacts of lifelong HIV and long-term ART on a number of health outcomes.

## Case studies of interventions designed to address specified needs

The following case studies illustrate some ways in which services have responded to identified needs. They provide examples of collaboration between different services, and/or of interventions that aim, or may be adapted, to reach young people who find it difficult to access or engage with services.

This example outlines how one peer mentoring scheme in clinics works.

### **Body & Soul Peer Mentoring at St George's and St Thomas' Hospitals**

Body & Soul is a London-based charity providing support to children, young people and families living with HIV. Body & Soul's peer support outreach service is a statutory/voluntary sector partnership model that aims to improve young people's emotional health, reduce isolation and improve engagement with clinical care and peer support.

In 2010, Body & Soul peer mentors began working in an HIV clinic at St George's Hospital in London; the scheme was extended to St Thomas' Hospital in London in 2011. Body & Soul peer mentors are 18–25 year olds living with HIV who work in the clinic setting to support young patients who are currently struggling in different aspects of their lives, e.g. attendance at clinic, adherence, and emotional and social well-being. Mentors are available to talk through issues, share their own experiences and encourage patients to attend appointments and access further peer support. Mentors are trained at Body & Soul and supervised and supported by Body & Soul and the clinic.

The main challenges involved in setting up this service have been ensuring all mentors had health checks and immunisations; delivering training on a small budget; and the logistics of guaranteeing the availability of mentors for all clinics.

An internal evaluation of the service at St George's found that patients reported finding the service emotionally rewarding. Fewer appointments were missed following the intervention. Condoms, contraception and HIV disclosure were the topics patients found most helpful to discuss with their peer mentor. Two patients said that speaking to a peer mentor had improved their physical health. One patient said, 'They encouraged me to have a better diet so I eat less junk food and cook my own food when I can.'

Overall the service was rated as 4/5 (median score) by 18 patients. Of those surveyed, 100 per cent would like the service to continue. Feedback from the clinical staff and peer mentors themselves has been excellent.

[www.bodyandsoulcharity.org](http://www.bodyandsoulcharity.org) | 020 7923 6880 |  
Contact Nimisha Tanna: [nimisha@bodyandsoulcharity.org](mailto:nimisha@bodyandsoulcharity.org)

This example explores the role of young people in supporting each other.

### **Positively UK Peer Youth Case Worker**

*This text was written by Positively UK's Peer Youth Case Worker.*

I became a Peer Youth Case Worker for Positively UK having seen the amazing things they were able to achieve in their work as peer supporters and case work leaders. I support young people living with HIV in the UK aged 13–25, holding support groups and empowering them with my story.

When I was disclosed to, I chose to block out any positive facts about what doctors were telling me and was stuck in 'doom' mode. Over the years I was asked if I wanted to join support groups. I said 'No' until I was blue in the face. Then I was introduced to CHIVA, met some *amazing* and lifelong friends, and finally realised that I am *not* the only one who puts on a hard exterior and holds things in (due to fear). I went on to holding summer camps and speaking at worldwide conferences for other young people who were in the same boat. They looked up to me and wondered where I got my strength, courage and knowledge from?

Being able to walk into clinics and meet young people from all walks of life, knowing that they are able to take time out to sit with me is one of the most rewarding things I have experienced. It can be very emotional at times, you hear stories that can make you go away feeling drained and all you want to do is take all the pain and struggles away from that client. Unfortunately you can't. All you can do is be there for them, monitor their progress, refer them to organisations who may be able to help, and remain compassionate. I believe peer support is one of the best things a person living with *any* chronic illness can be exposed to. Just knowing that there are people out there who are on the same rollercoaster ride as yourself and they are there to hear you out is life changing. There are times when all you want to do is confide in a loved one about the situations you are going through, but fear that they may not understand, even worse discriminate against you. Having a peer support worker is the next best thing. At times, patients may not want to speak to a complete stranger about their HIV status. It's a big step for them to open up to someone alien to them, especially if they are still getting their head around living with HIV. However there is nothing more rewarding than having that person who was full of fear and discouragement come back in a few months' time with a positive mindset, enquiring about volunteering as a peer support worker.

At Positively UK we have a great team of peer caseworkers who are not only supporting their clients, but have the heart, time and passion to support their colleagues at the end of a long day's work. Training enables each peer caseworker to gain further knowledge on HIV and treatments.

I'd be lying if I said I don't have my off days, sad hours and scary moments. However I have learnt to embrace my status, and make a difference to young people like myself who may have a few more off days, sad hours and scary moments than I do. I couldn't ask for a better career.

[www.positivelyuk.org](http://www.positivelyuk.org) | 020 7713 0222 | [info@positivelyuk.org](mailto:info@positivelyuk.org)

Below is an example of a national project that works to improve access to peer support for young people who cannot or do not access local groups, and that involves collaboration with a range of services and practitioners.

### **CHIVA Support Camp**

The Children's HIV Association (CHIVA) functions as a network for health and social care practitioners supporting children and families living with HIV. CHIVA also runs projects working directly with young people, one of which is a Support Camp for up to 100 HIV positive young people aged 13–17. Camps were run in 2010 and 2011 and, funding permitting, will continue annually. The first two years of Support Camp have seen 138 different 13–17 year olds attend camp. Nineteen different HIV positive young people aged 18–24 have attended as camp leaders.

The five-day camp programme is run in collaboration with a number of different individuals and services that bring expertise in health, sexual health and HIV. One of its primary aims is to enable the development of peer friendships and networks to address social isolation. Young people are referred, via health and voluntary sector services, to attend from across the UK and Ireland. Young people who do not access peer support are prioritised, and particular consideration is taken of those living outside of urban centres in low prevalence areas with no access to peer support.

The camp also aims to increase knowledge and understanding of living well with HIV through youth-friendly workshops on topics chosen by young people. HIV is openly discussed from the outset, and young people have commented that knowing that all attendees are HIV positive is liberating. Creative activities leading to performances, and outward bound activities, are provided with the intention of enhancing confidence and self-esteem.

Additionally, the camp involves and provides development opportunities for young adults living with HIV through the Camp Leaders Programme, which offers OCN accredited training in youth work to equip them to support their younger peers at camp. Camp leaders and older HIV positive volunteers provide attendees with access to a broader community of people living with HIV, from whom knowledge, support and inspiration can be gained.

Key practical considerations involved in setting up and running Support Camp have been putting the necessary policies and procedures in place, and managing medication. The main challenge is funding the camp. It is also necessary for CHIVA to pay for and organise attendees' travel, which depends on the help of people working in the sector, who act as escorts.

The 2010 camp was evaluated by Sigma Research using questionnaires before, during and after camp. The evaluation found that the camp 'was regarded by almost all participants as an exceptionally positive, esteem-boosting, beneficial experience'. Three months after camp, 97 per cent of respondents were in contact with friends made there. Two-thirds reported an increase in the range of people they spoke to about HIV (Dodds 2011).

[www.chiva.org.uk](http://www.chiva.org.uk) | 0117 315 5100 |

Contact Magda Conway: [magda.conway@chiva.org.uk](mailto:magda.conway@chiva.org.uk)

The example below shows voluntary sector and health practitioners working together on a new intervention designed to support young people experiencing difficulties with adherence to treatment.

**Gregory's Place Barnardo's and North Manchester General Hospital (NMGH) 'Medication Group'**

Gregory's Place Barnardo's supports children, young people and families affected by HIV in the Manchester area. In 2011 Hester Cox, Social Worker at Gregory's Place, and Katie Rowson, Paediatric HIV Nurse Specialist at NMGH, undertook a joint initiative aimed at addressing the issues, worries, questions and emotional support needs of young people who struggled with treatment adherence, and providing practical tips to promote adherence.

Hester and Katie set up a 'Medication Group' of four young people. Each group member was aware of her HIV diagnosis, was a service user of both Gregory's Place and NMGH, and experienced issues with adherence to ART. All members wanted to participate and hoped to improve their adherence. Taxis were used to maximise attendance: this was a key expense.

Medication Group met for five informal sessions. Members completed motivational questionnaires in the first and final sessions. They were invited to ask questions and lead discussions, and were also encouraged to bring medication to each session and fill their dosette boxes together.

In the first meeting, the group discussed challenges around adherence and what helped them to remember medication. The second session explored how HIV affects the body, how ARVs work, and consequences of not taking treatment. The third session included a self-esteem exercise and verbal evaluation of the programme so far. For the fourth session, the group visited a pharmacy and explored medicines further, including the need for multiple pills and for certain requirements (for example taking medicines with or without food). The final session served as a recap on concepts such as CD4 count and viral load, and provided young people with information resources from NAM, i-Base and the website Pozitude.co.uk.

The information given in Medication Group was not necessarily new to members, but it was noticed that young people asked questions that they had been told the answers to many times before: they needed to be ready to understand. Hester and Katie also found that some members needed constant support with treatment from parents/carers and/or professionals.

It was felt that the small group worked well. All members were female, and this may have enabled more open discussion than would have been possible in a mixed group. Young people's motivational questionnaire answers from the final session showed some improvement, and they wanted the group to continue longer term. For some, the most helpful factor seemed to be the opportunity for additional peer and professional support.

The collaboration between Barnardo's and NMGH was constructive and it is envisaged that further group work to support adherence will be needed.

[www.barnardos.org.uk](http://www.barnardos.org.uk) | Contact Hester Cox: [hester.cox@barnardos.org.uk](mailto:hester.cox@barnardos.org.uk)

In this final example, health practitioners lead a programme of group work with young people. Periodic events for young people referred via health services show another approach to aiming to address the issue of isolation.

### **The Looking Forward Project**

The Looking Forward Project (LFP) was created in 2004 and is embedded within a family HIV clinic in the London Borough of Newham. The project is for young people living with HIV who are over 12 years of age and know their diagnosis. It consists of three structured events per year. These 'Looking Forward Days' are led by Clinical Psychologists and an HIV Clinical Nurse Specialist with input from a range of other practitioners. About 45 young people are registered with the project, and maximum attendance at a single event tends to be around half this number. Eligibility is based on where a young person lives or accesses care, but is somewhat flexible.

'Looking Forward Days' are held in a non-clinical environment. A variety of teaching, drama and discussion-based activities are used, some led by older members of the group. Sessions address topics such as HIV treatment and sex and relationships, and support positive health-related behaviours and the development of coping skills and strategies.

One key challenge was overcoming practitioners' concerns about the suitability of some of the content for younger participants, as facilitating frank discussions about sexual issues and condoms was an integral part of the events. Obtaining funding to provide lunch at a restaurant has also been difficult, as has finding the time for important ongoing evaluation.

The LFP team carried out an evaluation of the programme in 2007. Six 'Looking Forward Day' attendees aged 13–15 were interviewed. Young people felt that receiving a personally addressed invitation was important; that lunch at a restaurant and a voucher were strong incentives to attend; that learning in a stimulating context that didn't feel school-like was appreciated. They found it helpful to meet other young people living with HIV, but 'tended to speak about their own and others' status in an oblique manner and often avoided using the term "HIV"'. Several young people reported greater acceptance of medication after attending (Campbell and others 2010).

Contact Dr Tomás Campbell at Newham Psychological Services:  
tomas.campbell@eastlondon.nhs.uk | 020 8536 2165



## Conclusions

Young people living with HIV in the UK have a wide range of characteristics, life histories, experiences of living with HIV, and challenges. Young people are entering adult services with some complex health and psychosocial support needs, and transition is a critical time in terms of establishing positive engagement with services and strong self-management and life skills.

Findings from consultation with young people, practitioners and parents and carers highlight, first and foremost, that young people living with HIV want to be seen and treated as 'normal', and receive support that helps to minimise the interference of HIV in their lives. Findings suggest that transition experiences are complex and variable. Stigma emerged as a key element of how HIV impacts on young people as they grow up. Challenges were presented by a reliance on specialist HIV services, as many young people fear possible stigma, discrimination, breaches of confidentiality and lack of understanding outside HIV services.

Relationships with practitioners, families and peers are significant and were key determinants of achieving health and well-being for the young people spoken to here, indicating the importance of good communication between practitioners and parents and carers. Communication with young people is also crucial, with young people benefiting from transparent and responsive communication about HIV within relationships that feel comfortable and are not solely focused on HIV. Environments in which clinics take place also have a strong effect on young people's feelings about accessing HIV care. Wider contexts are also very important, for example distance and location.

Young adults expressed some significant challenges and obstacles. Some could be described as practical concerns, for example financial difficulties and unemployment; others, such as treatment effects and social isolation, seemed closely associated with impact of HIV on their lives.

Many practitioners reported practical constraints to supporting young people living with HIV, primarily funding, time, geography and small numbers of clients or patients. These barriers are difficult to overcome, and commissioning and funding decisions should seek to support practitioners in working around them as far as possible.

## Recommendations for transition practice and service development

The following recommendations are based on the findings from the consultation groups along with a review of available literature and guidance.

### *Access to appropriate services for young people*

- Services and practitioners should be aware of the diversity of individual circumstances, experiences and needs amongst young people with vertically and horizontally acquired HIV
- Young people should have meaningful involvement in service development and delivery
- Adult services should be mindful of young people's lifestyles, routines, interests and ways of communicating, and respond to these as far as possible
- Eligibility criteria and geographical boundaries should be flexible
- All young people should have access to opportunities for peer support; those who are unable or choose not to engage must be able to get information, advice and emotional support in other ways
- Young people should be involved in producing resources for young people, which should be made widely accessible
- Creative approaches are needed to provide 'young people friendly' service environments
- Young adults living with HIV have some distinct needs that are different from those of younger people: services should continuously review how to best meet these needs

### *Developing independence and self-management skills*

- Services for young people living with HIV should promote independence and self-determination, and should address the 'whole person'
- As practitioners continue to explore how approaches to disclosure to children and young people can best meet their needs, the exchange of ideas and expertise will be highly valuable
- Potential anxiety or reluctance around transition should be mitigated through planning ahead; familiarising young people with the process; involving them and offering choices; and acknowledging the difficulties of 'letting go' and forming new relationships for young people, practitioners and parents/carers
- A range of services, practitioners and resources are likely to be needed to support young people's learning about HIV and sexual health to reflect different stages of development, learning styles and ways of engaging
- Work around health, including on adherence, must address practical and emotional aspects of living with HIV and taking HIV treatment

- Practitioners should be aware of the benefits of normalising HIV and of supporting young people to make use of non-specialist as well as specialist services

### ***Supporting the family***

- Statutory social care services should empower parents and carers to help young people in transition through healthy, cohesive families
- Parents and carers need opportunities to access information and assistance around transition, particularly in relation to health services, as well as disclosure and discussing sex and relationships; this should be culturally appropriate
- Services involved with young people should aim to support positive relationships between young people and their families
- Feedback from parents and carers should be taken into account when developing services and practice

### ***Improving coordination***

- Transition pathways should be clear, with named individuals leading on transition between services
- Effective collaboration and communication between children's and adult services, services from different sectors, and practitioners in multidisciplinary teams is necessary to ensure smooth transitions
- Practitioners, young people and parents and carers all need access to information on services and transition arrangements
- Practitioners require full information on what services and resources are available for the young people with whom they are working

### ***Professional development***

- Practitioners can improve transition by sharing their experience and tools with each other
- Practitioners should be given opportunities to develop skills, particularly in communicating with young people; working with parents and carers; providing sexual health advice; and, for those working in adult services, understanding medical, social and emotional aspects of growing up with HIV
- Practitioners with expertise in HIV should be supported to develop understanding of HIV amongst other practitioners.

## **Policy recommendations**

Current changes to the landscape of health and social care services should ensure that effective work on transition for young people living with HIV can continue, and should be used as an opportunity to make improvements where possible.

The new NHS Commissioning Board should champion effective transition arrangements for young people with HIV, including clarifying the role that

clinical senates, intended to provide expert advice to inform commissioning decisions, can play in promoting better collaboration across the services these young people need and use.

By October 2012, Health Watch England and local Health Watch in every local authority area will be established to promote patient and public involvement in decisions about health and social care services. The Department of Health should work with partners to explore how young people living with HIV can use these mechanisms to influence the development of services, and to ensure they are accessible for this group of young people.

The needs of young people living with HIV and their families should be taken into account by Health and Wellbeing Boards when preparing Joint Strategic Needs Assessments (JSNAs) and Joint Health and Wellbeing Strategies (JHWSs) for their local areas, and by the NHS Commissioning Board when commissioning services. Local Health and Wellbeing Boards should be responsible for ensuring effective coordination and collaboration between the range of health, social care, education and other services needed by young people living with HIV. This should be reflected in statutory guidance provided to Health and Wellbeing Boards.

Any quality standards for NHS care, public health and social care for people living with HIV that may be developed by the National Institute for Health and Clinical Excellence (NICE) should take into account the needs of young people living with HIV in transition.

Ensuring the wider health and social care workforce have a solid understanding of the needs of young people with HIV must be a priority for Health Education England, which will provide oversight for NHS education and training from April 2013. The Department for Education and Social Work Reform Board should ensure that the revised social work curriculum and continued professional development frameworks provide children and young people's social workers with a broad understanding of the specific circumstances and needs of young people living with HIV.

The Department for Education must ensure that its proposals following the current review of personal, social, health and economic (PSHE) education address the need to educate young people about the scientific, health and social aspects of HIV.

Government should take action to ensure that voluntary sector organisations working effectively to support young people with HIV are not disproportionately disadvantaged by restrictions on public spending, including helping these organisations to demonstrate their impact and value-for-money and to diversify their funding base.

## References

Blum, RW and others (1993) 'Transition from child-centered to adult healthcare systems for adolescents with chronic conditions. A position paper of the Society for Adolescent Medicine', *Journal of Adolescent Health*, 14, 7, 570–6.

Campbell, T and others (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*, 22, 2, 263–9.

Collaborative HIV Paediatric Study (CHIPS) (2011) *Annual Report 2010/11 (June 2011) and CHIPS UK & Ireland Slide Set 2010–11* [online], Available from: [http://www.chipscohort.ac.uk/summary\\_data.asp](http://www.chipscohort.ac.uk/summary_data.asp) [Accessed: 4.11.2011].

Croucher, A and others (2011) *Sexual and reproductive health in adults perinatally infected with HIV: audit of a single centre cohort: 5th annual Children's HIV Association conference, Cardiff, abstract P6* [online], Available from: <http://www.chiva.org.uk/professionals/health/events/previous/conference11/posters.html> [Accessed: 4.11.2011].

Curtis, H on behalf of the British HIV Association (2010) *Adolescent transition to adult HIV care: Presentation at the British HIV Association Autumn Conference 2010 CHIVA Parallel Sessions, London* [online], Available from: <http://www.chiva.org.uk/presentations/chivaoct10/curtis/curtis.pdf> [Accessed: 4.11.2011].

Department of Health (2004) *National Service Framework for Children Young People and Maternity Services: Key Issues for Primary Care*, DH, p.7 (Standard 4: Growing Up into Adulthood).

Department of Health (2011) *You're Welcome – Quality criteria for young people friendly health services – 2011 Edition* [online], DH, Available from: [http://www.dh.gov.uk/dr\\_consum\\_dh/groups/dh\\_digitalassets/documents/digitalasset/dh\\_127632.pdf](http://www.dh.gov.uk/dr_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_127632.pdf) [Accessed: 4.11.2011].

Dodds, C (2011) *Freedom to Be (F2B) summer camp: outcome evaluation* [online], Sigma Research, Available from: <http://www.sigmaresearch.org.uk/go.php?/reports/report2011a> [Accessed: 4.11.2011].

Foster, C and others, and Collaborative HIV Paediatric Study (CHIPS) (2009), 'Young people in the United Kingdom and Ireland with perinatally acquired HIV: the paediatric legacy for adult services', *AIDS Patient Care and STDs*, 23, 3, 159–66.

Foster, C (2010) *CHIVA Guidance on Transition for adolescents living with HIV* [online], Children's HIV Association of the UK & Ireland, Available from: <http://chiva.org.uk/professionals/health/guidelines/youngpeople/transition.html> [Accessed: 4.11.2011].

Frize, G and others (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*, 12 (Suppl. 1): 70–1 [online], Available from: <http://www.bhiva.org/documents/Conferences/Bournemouth2011/HIVMedicine12.pdf> [Accessed: 4.11.2011].

Health Protection Agency (2007) *Testing Times – HIV and other Sexually Transmitted Infections in the United Kingdom: 2007*, HPA, p. 97–98.

Health Protection Agency (2010) *HIV in the United Kingdom: 2010 Report. Health Protection Report 2010 4(47)*, HPA, p. 6.

Howell, S and Hamblin, E (2011) *Young people living with HIV and the transition from children's to adults' services: Literature review* [online], National Children's Bureau, Available from: <http://www.ncb.org.uk/hiv/resources> [Accessed: 4.11.2011].

Kent, A, Foster, C and Fidler, S (2011) 'How do patterns of antiretroviral adherence in a childhood impact on adherence in adult life?': 17th annual British HIV Association conference, Bournemouth, abstract P59, British HIV Association, *HIV Medicine*, 12 (Suppl. 1): 34 [online], Available from: <http://www.bhiva.org/documents/Conferences/Bournemouth2011/HIVMedicine12.pdf> [Accessed: 4.11.2011].

McDonald, S and others (2011) 'Young people and self-reported adherence to antiretroviral therapy: a HYPNet survey': 17th annual British HIV Association conference, Bournemouth, abstract P198, British HIV Association, *HIV Medicine*, 12 (Suppl. 1): 81–2 [online], Available from: <http://www.bhiva.org/documents/Conferences/Bournemouth2011/HIVMedicine12.pdf> [Accessed: 4.11.2011].

Melvin, D, Donaghy, S and Conway, M (2008) *Talking to children about their health and HIV diagnosis* [online], Children's HIV Association of the UK & Ireland, Available from: <http://www.chiva.org.uk/health/guidelines/talking> [Accessed: 4.11.2011].

Office of the Deputy Prime Minister (2005) *Transitions: Young Adults with Complex Needs: A Social Exclusion Unit Final Report* [online], ODPM Publications, Available from: <http://www.communities.gov.uk/publications/corporate/transitionsyoungadults> [Accessed: 4.11.2011].

Parameswaran, Y and others (2010) 'High rates of asymptomatic neurocognitive impairment are observed in perinatally HIV-infected adolescents', *JAIDS Journal of Acquired Immune Deficiency Syndromes*, 55(1): 134–6 [online], Available from:

[http://journals.lww.com/jaids/Fulltext/2010/09010/High\\_Rates\\_of\\_Asymptomatic\\_Neurocognitive.19.aspx](http://journals.lww.com/jaids/Fulltext/2010/09010/High_Rates_of_Asymptomatic_Neurocognitive.19.aspx) [Accessed: 4.11.2011].

Pebody, R (2009) 'The Swiss statement', *HIV Transmission and Testing* [online], NAM, Available from: <http://www.aidsmap.com/The-Swiss-statement/page/1322904/> [Accessed: 4.11.2011].

Royal College of Paediatrics and Child Health (2003) *Bridging the Gaps: Health Care for Adolescents*, RCPCH, London.

Seery, P (2010) 'The sexual health of young people in the UK who acquired HIV at birth', *HIV Nursing*, 3(10):8–12 [online], Available from: [http://findarticles.com/p/articles/mi\\_6821/is\\_3\\_10/ai\\_n57163687/?tag=content;col1](http://findarticles.com/p/articles/mi_6821/is_3_10/ai_n57163687/?tag=content;col1) [Accessed: 4.11.2011].

Smith, A and Body & Soul Charity (2011) *Sexual risk behaviour amongst adolescents living with or affected by HIV*, 5th annual Children's HIV Association conference, Cardiff, abstract P9 [online], Available from: <http://www.chiva.org.uk/professionals/health/events/previous/conference11/posters.html> [Accessed: 4.11.2011].

Survey of Prevalent HIV Infections Diagnosed (SOPHID) (2010a) *HIV-diagnosed persons seen for HIV care: Young adults data tables* [online], Available from: <http://www.hpa.org.uk/Topics/InfectiousDiseases/InfectionsAZ/HIV/> [Accessed: 4.11.2011]. See Tables 1, 2, 3 and 4.

Survey of Prevalent HIV Infections Diagnosed (SOPHID) (2010b) *Data tables 2010: National Tables by SHA of Residence* [online], Available from: <http://www.hpa.org.uk/Topics/InfectiousDiseases/InfectionsAZ/HIV/> [Accessed: 4.11.2011]. See Table 1.

Survey of Prevalent HIV Infections Diagnosed (SOPHID) (2011a) *United Kingdom New HIV Diagnoses to end of June 2011: Young Adults* [online], Available from: <http://www.hpa.org.uk/Topics/InfectiousDiseases/InfectionsAZ/HIV/> [Accessed: 4.11.2011]. See Tables 2, 3, 4 and 5.

Survey of Prevalent HIV Infections Diagnosed (SOPHID) (2011b) *United Kingdom New HIV Diagnoses to end of June 2011* [online], Available from: <http://www.hpa.org.uk/Topics/InfectiousDiseases/InfectionsAZ/HIV/> [Accessed: 4.11.2011]. See Table 1.

Williams, B and others on behalf of HYPNet (2010) *Pregnancy outcomes in women growing up with HIV acquired perinatally or in early childhood*. Second Joint Conference of the British HIV Association and the British Association for Sexual Health and HIV, Manchester, abstract P144 [online], Available from: <http://www.hypnet.org.uk/files/BHIVA%20poster%20jk120410PTcf.pdf> [Accessed: 4.11.2011].

# Just Normal Young People

## Supporting young people living with HIV in their transition to adulthood

A report from the Children and Young People HIV Network

Emily Hamblin

Children who have grown up with HIV are increasingly entering adulthood. Young people are also acquiring HIV in adolescence and early adulthood. With this in mind, practitioners and services are aware of the need to support young people living with HIV in their transition into adult life and adult-oriented services.

This report examines transition in the context of HIV in depth, presenting experiences reported by young people, practitioners, parents and carers. It draws upon these findings to explore how the needs of young people in transition can be met effectively.

The report is part of a Children and Young People HIV Network project aiming to enable improved transition experiences for young people living with HIV. The Network brings together a wide range of organisations and practitioners concerned with children and young people who are living with and/or affected by HIV. It includes members from health, social care and voluntary sector services working with children and adults. One of the primary aims of the Network is to develop policy and practice recommendations and associated tools and resources. Consultation with young people and those who support them, and participation from young people in Network activities, are central to this work.



National Children's Bureau  
8 Wakley Street  
London EC1V 7QE

tel +44 (0)20 7843 6000  
fax +44 (0)20 7278 9512

Registered Charity Number 258825

#### Useful numbers

Book Sales: 0845 458 9910  
Conferences and Training: 020 7843 6041  
Fundraising: 020 7843 6329  
Information Centre: 020 7843 6008  
Membership: 020 7843 6080  
Young NCB: 020 7843 6099

[www.ncb.org.uk](http://www.ncb.org.uk)