

Just Normal Young People

Supporting young people living
with HIV in their transition to adulthood

Young people's report

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Children and
Young People
HIV Network



Children and Young People HIV Network

The Children and Young People HIV Network is for people who work with children and young people who are living with or affected by HIV, and it works with young people themselves to give them a voice. It aims to improve the lives of children and young people, and develop the support they get.

The Network has a website where you can find more information:

www.ncb.org.uk/hiv

Acknowledgements

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For a complete list of all those who helped us develop and share this report, please see the full report, *Just Normal Young People: Supporting young people living with HIV in their transition to adulthood*. It's available on the Network website www.ncb.org.uk/hiv

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

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Introduction

Children who have grown up with HIV are becoming adults. Some young people are also becoming infected with HIV. This means that services that work with both children and adults with HIV need to be able to support teenagers and young adults.

This report explores what it is like to grow up with HIV, and how different services can best meet the needs of young people. This report is for you:

- to help you understand what we call 'transition' (see page 5)
- to show you what some young people with HIV said about getting older and becoming more independent
- to show you what some professionals and parents and carers have said about supporting young people with HIV.

This report is based on a longer report, *Just Normal Young People: Supporting young people living with HIV in their transition to adulthood*. That report was written for anybody who works with young people who are HIV-positive, or makes decisions about the services young people with HIV use.

To produce this report, we spoke to:

- 45 young people with HIV aged 13–28, who lived across England and even other parts of the UK
- 123 professionals
- 4 parents and carers of young people with HIV.

Who are the 'professionals'?

You may have many professionals involved in your life, working for different services and organisations. Some work to look after your health (for example, HIV doctors, nurses, psychologists, GPs and many more). Some work with you to address specific needs you have in your life (for example social workers or support workers in HIV organisations). Almost all of the people who took part in this project came from those groups. 'Services' are the things these people do.

You may also know various other professionals. Some might be there to help you achieve things in life (for example, teachers); others might give you advice or decide whether you can receive certain benefits or services; others might make decisions about what you can do (for example, immigration authorities or the police).

Who are young people with HIV?

In 2011, there were 1,190 children with HIV in the UK and Ireland who were in paediatric HIV care (paediatric is a health word which means 'for children'). There were also 305 young people who had been in paediatric care, but had grown up and moved into adult services (CHIPS 2011). Many will be in their 20s now. The average age young people leave paediatric care and move up to adult care is 17 (Foster and others 2009).

Most teenagers with HIV in the UK and Ireland have grown up with HIV since they were born, or very young. 8 out of 10 children growing up with HIV in the UK are from Black African communities. Just over half live in London, with the remainder living in different parts of the UK and Ireland. There are also some young people with HIV who became infected in ways other than mother-to-child transmission.

In 2010, the average age of a child with HIV was 12.

What is on young people's minds as they grow up?

All the same things as any young people are thinking about, plus a few more! Here are some of the topics which young people covered when they spoke to us about their experiences of entering adulthood:

- Mental and emotional wellbeing
- Physical changes
- Identity and culture
- Peer pressure and changing friendships
- Relationships, sex, and sexuality
- More freedom as well as greater responsibility
- Exams, education options, and maybe going to university
- Starting work and thinking about careers
- Maybe becoming a parent now or in the future
- Faith
- HIV treatment
- Stigma and confidentiality
- Money and benefits
- Housing
- The law, and the justice system
- Life skills
- Lifestyle choices – for example diet
- Motivation
- Self-esteem.

Different things will be more or less important for different people or at different stages.

Introducing transition

What does the word 'transition' mean?

1. *change or passage from one state or stage to another*
2. *the period of time during which something changes from one state or stage to another*

- Collins English Dictionary

The word 'transition' is used by professionals working with young people with HIV and many other long-term conditions. It means the process by which a young person moves from services that work with children to services that work with adults. In this report, we'll talk about transition in relation to:

- a young person's whole journey from childhood to adulthood
- how *any relevant* services or support that a young person uses might change as he or she gets older.

Transition from children's to adult services is supposed to be a planned process that happens over a period of time. A young person should have a chance to prepare for letting go of some familiar people who have provided support, beginning to work with some new people, being in a new environment and adapting to more adult ways of doing things.

Professionals have guidance to help them support young people through transition.

There are lots of different services that work with young people, but for now we will look at the three main types of services that provide support around living with HIV.

Transition in health services

Most health professionals either work with children (in paediatric services) or with adults. People with HIV get looked after in a range of settings, and understanding what kind of service you're in can help you know what to expect.

Eventually, when young people who have been using children's health services grow up, they need to move on to an adult service. Some people make a direct move from a children's service into an adult service, either in the same hospital or area, or in another place they have chosen.

Some people have special transition clinics, or clinics specifically designed for young people. This is like a bridge between children's and adult services.

The two most common settings in which adults get their HIV care are:

- Infectious Diseases (ID) hospital departments, which also treat people with other conditions, such as tuberculosis
- Sexual health or genitourinary (GUM) departments or clinics, which also see patients with other conditions.

In many areas we found that people could choose between these two different clinics and people had different reasons for choosing between them. For example there may be other members of your family who have HIV and they get their health care at a particular clinic. How do you feel about having your health care at the same clinic? Some people may prefer this and others may want to be at a different clinic. You can't always choose, but it's important to know that sometimes you can.

In either of these services, there may be special HIV clinics where only people with HIV are booked in for appointments.

Children's and adult health services may look and feel quite different, and people might talk to you differently. See page 11 for more on what young people say about this, and what helps people settle in to new services.

Transition in HIV support services

Individual young people will have different levels of involvement with HIV support organisations. These organisations may provide a range of services, including peer support, group activities, one-to-one help and advice, day and residential trips, information and web-based services.

What is peer support?

Peer support is support which involves other people who are in a similar situation to you – other young people living with HIV. This may be in a regular group, at a residential camp, in an online network, or one-to-one with a young person acting as a mentor to another young person.

Many young people move on from young people's support services in a gradual and natural way, often keeping friends they have made there. Some people may need a little more one-to-one support. Many young adults become volunteers within their services, acting as leaders and role models for younger members.

Transition in social care

Some young people have support from social care services. This may be social workers for families experiencing difficulties; social workers for young people in care; help around living with disabilities that impact on everyday activities; or specific help around living with HIV.

Social care professionals tend to have less flexibility than some other professionals over who they can work with. For many young people, transition in social care is about trying to prepare to be able to manage without that service.

However, this is very different from one person to another. If you have a social worker, he or she will be able to explain more.

The main thing to remember is that the professionals – like social workers – who work with you are meant to help prepare you for changes which may happen in the future, like stopping a service when you become an adult.

You might want to ask them questions about this before the time comes, and this gives you the time to work out if you still need the help and where else you may be able to get it from.

If you are looked after by your local authority so you don't live with your parents, social workers have to continue to provide you with some support until you are 24.

Experiences

Here are some of the key things the young people, professionals and parents and carers said about transition.

What young people see in the future

The young people we spoke to talked most about education, raising children, getting into particular careers and having a good place to live. Young people did describe the different ways in which HIV may or may not impact on them achieving these things. For some HIV was also a source of inspiration. There were lots of plans and dreams for the future, including several books to be written! Some people felt more optimistic than others. Here are some quotes from young people we spoke to:

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'.

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

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

[I want to] be an ambassador for HIV.

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.'

One important point is that young people do not stop needing help on their 18th birthdays. People in their 20s had some separate interests and concerns from younger people, and so needed some different support.

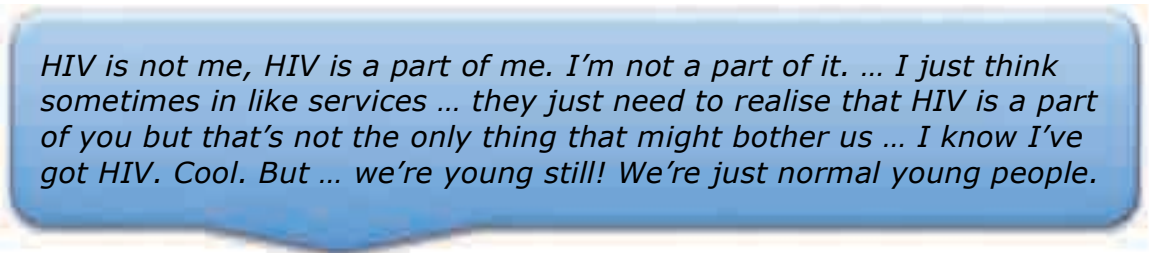
A range of services is available to help young people achieve their goals and deal with challenges in their lives. We have listed some websites at the end of this report which you might find useful.

Different young people

Young people with HIV come from lots of different backgrounds. They have different personalities, life histories, family lives, and experiences of HIV. Some were born in the UK; some were not. Some have had HIV since birth; others have been infected or diagnosed at an older age. This means that the process of becoming an adult with HIV can vary a lot from person to person.

'Just normal young people'

Young people wanted professionals to remember that they are like other people their age.



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.

Mental wellbeing

Young people, professionals, parents and carers talked about the impact of living with HIV on the mind as well as the body, and other issues in life which affect mental wellbeing, such as moving to a new country or losing a family member. People talked about the need to come to terms with HIV and how this is a journey rather than a moment, with steps forward and setbacks at different times.

Stigma

Everybody felt that stigma made growing up with HIV much more difficult.

As young people become older there can be more situations which make them think about telling another person that they have HIV: for example getting into a serious relationship, or moving out.

Professionals saw how worried young people could feel about other people knowing their HIV status, and wanted to help them keep control of their HIV information. At the same time, they wanted to encourage the idea that HIV is not something to be ashamed of.

On the following pages, you'll see comments from young people with HIV about different aspects of transition.

Talking about HIV

Being able to talk comfortably about HIV made a real difference to how young people coped with living with HIV. It was clear that young people benefited from having on going opportunities to talk about HIV as they grew older. This was important with both their family members and also with health professionals and others supporting them.

Ever since I was growing up, my mum would tell me like little stuff about it ... I preferred ... knowing more about it, ... not just me having to be curious ... It was easier for me to take the medication.

Normally [my dad] was there and he would be the one asking the questions like, 'How's my blood doing?... 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.

[Give us information about HIV] in stages because it's not all about cramming everything in and chucking stuff at us every single time. ... It will one day mean something more to me and I'll look back and be like, 'What did they say again?'

He's always there... I just tell my dad everything and he tries his best to help me even if he doesn't quite understand.

Getting used to leaving familiar services and using new ones

Here are some things which young people, professionals and parents and carers said were helpful for young people leaving children's health care and moving into adult clinics:

- Knowing beforehand what you can expect: Where will you be moving to? Do you have a choice in where you will be looked after as an adult?
- Meeting some of the adult staff before you move: they maybe able to come and visit you at the children's clinic or you may be able to go and visit them at the adult clinic
- Sometimes the children's staff can keep in touch with you for a while to help you settle into the adult clinic.

Here are some comments from young people on moving to adult clinics.

I call [my paediatric nurse] my auntie in a way. She's like part of my family, like, I couldn't imagine my life without her.

[The adult clinic is] all right, I guess, it's a bit gloomy but... It's not as fun as the children's one.

I've always gone to adults and they're nice there, they always ask me about school and remembered about my exams.

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.

At first [going to the adult clinic] 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.

Becoming more independent

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

- Going in to clinic appointments alone
- Taking medication without needing to be reminded
- Making decisions to talk to friends and partners about HIV.

That's life. Taking responsibility for the things that you do ... You're not going to get sick straight away so you can ... 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. ... My routine in the evening: I brush my teeth, I take my medicine and I go to bed.

*[My doctor] 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**.*

I mostly have to be reminded to take my medicine ... My social worker usually knows [my appointments] and she'll like remind me. ... I'll probably get a shock when I move.

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.

Ever since I knew, I was given a choice by my mother. She'd say, ... 'You know who you trust ... 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.'

Supporting each other

Young people, professionals, and parents and carers often said that peer support was really valuable for young people with HIV – both those receiving support or looking up to older role models, and those acting as leaders or mentors. However, not all young people want peer support. Others find that taking the first step of going to a group or camp can be scary, even if it's worth it.

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.

We actually do just talk about whether ... 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.

[When I went to peer support I] realised that I am not the only one who a 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 ... 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. (Peer Youth Case Worker at Positively UK – www.positivelyuk.org)

Families

All young people find that their family relationships alter as they get closer to adulthood. If a family is affected by HIV, sometimes this may affect how relationships change – for example, in terms of how parents and children understand each other's experience of HIV, or in terms of how young people caring for family members with HIV gain independence from the family.

Parents and carers, as well as brothers, sisters and other family members, are really important to most young people – whether they get to see these people often or ever, or whatever these relationships may be like. Lots of the young people we spoke to said that family members were their main source of support for living with HIV.

We spoke to some parents and carers to see what they thought about transition.

They felt that things that were going on in a young person's life, or for the wider family, had a strong impact on how the young person managed living with HIV. They said that having information and support for themselves really helped

parents and carers to be there for young people. HIV-positive adults could also be good role models for young people.

The parents and carers said that, when talking to young people about HIV, 'being as honest as possible helps'. They also felt it was really important for professionals as well as parents and carers to work together, and to listen to young people and what they wanted.

Professionals and their services

As the comments from young people show, people's experiences are very individual, and professionals knew this. They knew that young people had lots of different kinds of needs.

Some other things professionals talked about covered the types of things they try to do to help young people:

- trying to ensure there are enough resources to run really good services, or overcoming distances between services – this can be very difficult
- helping young people who find it difficult to take HIV medication – this is something that professionals worry about because a lot of young people find this difficult when they are growing up
- supporting young people who are isolated because of where they live, or how they feel
- making sure that everyone involved is working together to provide the best possible support, including people who work outside HIV services
- making sure to be sensitive to people's different cultural backgrounds
- supporting young people into early adulthood – in their 20s
- protecting confidentiality and helping people feel comfortable, without playing into the stigma by treating HIV like a bad secret – professionals want to show young people that there is no shame in being HIV-positive.

Professionals we talked to were very committed to their work with young people and saw themselves as playing really important roles in trying to reduce the impact of HIV on young people's lives and ensure they had full opportunities for achievements as they entered adulthood.

Conclusions

Key points from talking to young people, professionals and parents and carers are:

- It can be a big change for young people leaving children's services, like clinics, and moving to adult ones. This can be difficult and young adults may not feel they are looked after so much as when they were children.
- Young people want to be treated as 'normal' and live ordinary lives just like anybody else, where HIV doesn't take over. Young people have the same dreams and ambitions in their lives but they do worry about how HIV affects these.
- Stigma is a real problem. People worry a lot that other people don't understand HIV and will react badly to it. This does lead to most young people not sharing HIV with others very much.
- Most professionals are very aware of the issues involved in transition for young people with HIV, and very keen to understand how best they can support young people. Most clinics around the country do have plans about how they will help young people move and settle into adult clinics.

Recommendations

We made some recommendations for what would help. For professionals to think about and for young people themselves to think about:

- Young people with HIV should have access to a range of local, national and virtual services that meet their needs. Young people need to know about the kinds of services that are around them and what these may be able to offer them. Professionals who work with them can help young people learn about the different services around them and what is available online.
- Services should look at the whole young person and not just focus on HIV. Young people have a lot of different needs and goals. Professionals who work with them need to remember this. It's not always all about HIV.
- Young people are best supported when professionals and parents and carers work well together, and when professionals work well with each other.
- When the government makes changes to how health and social care services are set up, or cuts which affect support organisations, they should think about how young people with HIV will be supported.
- The government can address stigma through training for professionals who work with young people, and education in schools on HIV. Professionals can also help here by sharing their knowledge and understanding with others.

- Being able to talk about HIV somewhere – in your family, with your health professionals, with peers – is helpful. These conversations need to continue as you grow up, not just when HIV is named to you.
- Try to find someone you can talk to, who you can trust if you want to share any concerns.
- Communicate how you feel and what you need as much as you can – professionals will be better able to meet your needs if they understand where you are coming from.
- Try to spend some time, with the help of a support worker if you have one, thinking about the questions you have about getting older and living with HIV. Work out who can answer them. Your health professionals, support worker, social worker, your family, any HIV-positive friends? When you think about changes beforehand you can prepare for them and this can make change less scary and more in your control.
- There are some things you can't change – like getting older! – but you may have choices about where you are as an adult. It's important you know about what choices you have and are given the opportunities to make decisions.

Resources

We are going to produce some booklets for young people on different topics to do with growing up with HIV. Look out for these – they should be out later this year (2012).

There are different organisations working with young people with HIV, as well as printed and online information for young people. Ask someone who supports you with HIV about what's available for you. You may also like to check out these websites, all of which were developed with young people with HIV:

Body & Soul

This website has lots of information for young people on HIV, including podcasts, sound recordings, visual guides and stories and a blog.

www.bodyandsoulcharity.org

Children's HIV Association

This website has lots of information for young people as well as stories from young people and an 'ask a question' page. There is a secure site for HIV-positive young people which includes a social networking facility.

www.chiva.org.uk/youth/index.html

MyHIV

This website has an online community, reminder functions for medication and clinic appointments, online counselling and a way of privately storing information on your health. It has special content for young people.

www.myhiv.org.uk

Pozitude

This website has lots of information for young people on HIV as well as interviews with young people and an online forum.

www.pozitude.co.uk

References

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

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.

Hamblin, E, *Just Normal Young People: Supporting young people living with HIV in their transition to adulthood*, Available from: http://ncb.org.uk/media/496335/hiv_network_transition_report_final.pdf