



## Children and Young People HIV Network



- A national network that brings together a wide range of organisations and practitioners concerned with children and young people infected with and affected by HIV.
- Supports young people to make their voices heard through participation work.
- National and local policy and practice development, the development and dissemination of good practice and information resources, training and events, lobbying, advocacy and media work.




## The transition project

- 3 year project funded by the Department of Health
- Working with both children's and adults' workforces in health, social care and the voluntary sector
- Looking at whole person and all services
- Understand the range of practice and experience across the country
- Develop resources in response to identified needs
- Facilitate practice sharing and collaboration




## The consultation process

- Focus groups for 118 practitioners from children's and adult services in England and 5 from Wales – health, voluntary sector and statutory social care
- Interviews and consultation events with 33 young people aged 13-19 and 12 young adults aged 20-28 – Seven English regions plus one other UK country represented
- One small consultation with parents and carers
- What is your experience? What challenges do you face? What do you need?



## Findings

- Diversity of experience
- Some complex medical and psychosocial issues and needs
- Poor adherence and loss to follow-up in health
- Practical constraints
- When numbers are small, developing experience, establishing processes and getting resources/support
- Diagnosis in adolescence
- Social care can be difficult to access, or may be lost
- Too much depends on individuals
- Transition in voluntary sector services
- Poor understanding of HIV amongst other practitioners



## Getting the balance right

For each individual...	
Enough information Being sure to use information that is pitched at the right level	Not too much information The available information is not always appropriate for a person's age and level of understanding, but s/he still needs it
Acknowledging that a young person may be sexually active	Not assuming that a young person will be sexually active
Being supported by highly proactive professionals – e.g. chasing patients who DNA, providing transport	Developing independence and fitting into an adult environment with adult expectations
Recognising the importance and influence of parents	Enabling young people to 'flee the nest'
Addressing issues raised by HIV	Getting on with a life that doesn't revolve around HIV



## Good news!

Lots of young people:

- Found increasing independence empowering
- Were optimistic about their futures
- Found their families helped them through a lot
- Had received lots of support and useful information from services
- Felt pretty well in control of HIV
- Were comfortable with how practitioners talked to them about sex and relationships
- Really valued peer support and one-to-one work from voluntary sector services




All quotes are from Hamblin, E (2011) *Just Normal Young People: Supporting young people living with HIV in their transition to adulthood*, National Children's Bureau.

This report is available at [www.ncb.org.uk/hiv](http://www.ncb.org.uk/hiv)

Young people talked about...

## Keeping HIV in its place

'HIV is not me, HIV is a part of 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 [...] We're just normal young people.'




## Understanding what's going on

**Late naming**  
(Young person disclosed to at 15, upon starting treatment)  
'It was just afterwards, about a few months, as I was taking medicines, that's where it went wrong for me.'

**No naming**  
'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."'

**Transition**  
'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 to change as I get older.'

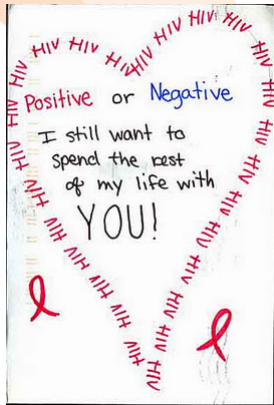


## Stigma

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

'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.'

'My friends were the ones saying, "Don't touch him, he's got HIV." I had to educate them.'



PostSecret

## Relationships with practitioners



'We've known each other since we were ten [...] She's like part of my family, like, I couldn't imagine my life without her.'

'I hate hospital. [...] I've had three appointments; I've had three different doctors. [...] 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."'

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

## Perceptions of adult services



'Everyone's just sat there, no one's smiling, it's in a grey hospital, everyone's like dead.'

'I just feel like they're just looking at me like, "What's she doing here?" I feel awkward.'



## Learning about HIV & sexual health



'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.”

'They speak in doctor language.'

'[My doctor] made it clear that actually anyone should always use a condom [...] You just kind of felt normal, rather than you should be doing something differently because of your status.'

## Peer support



'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.'

'I like being just free.'





## Parents and carers

**Respect**  
'We live with our children; we know them.'

**Dignity**  
'I'm not a victim of my circumstances constantly.'

**Support**  
'If you have a healthy parent or carer, you have a well looked after child.'



## Key principles

- Ensuring access to appropriate services for young people
- Preparing young people for change
- Developing independence and self-management skills
- Supporting the family
- Improving coordination
- Professional development



**Now...**

- You can:
  - Read and help disseminate the report
  - Encourage young people to get involved in developing resources
  - Share your experiences, views, expertise and tools
- We can:
  - Keep you up to date with news and opportunities from the sector, including on the transition project
  - Help you find information, resources and advice
  - Share your work with the sector
  - Feed your views into policy and practice development work

**Many thanks to the young people and practitioners in the Midlands who have taken part so far**



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