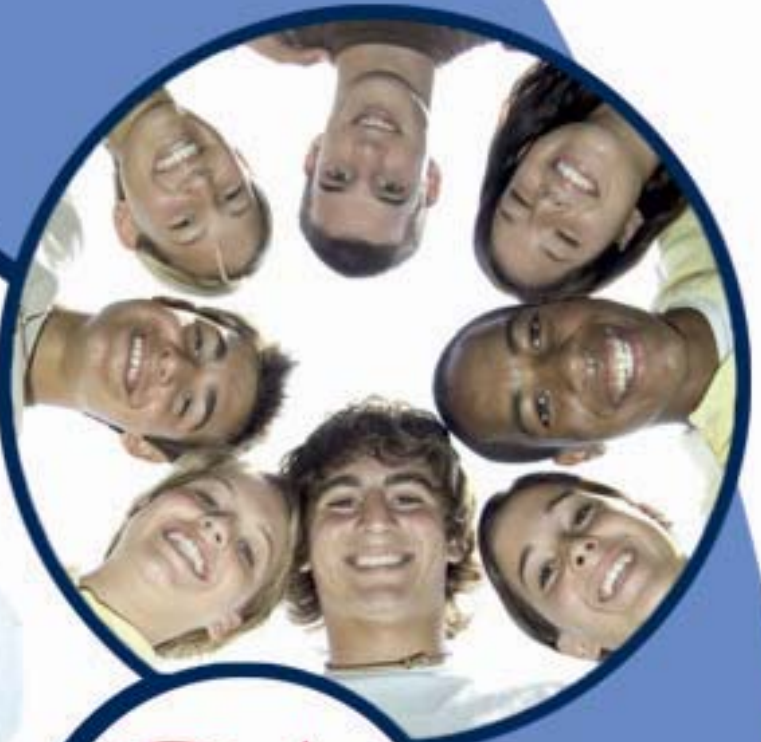


What Do Young People Think About Health Services

A report of a preliminary discussion meeting with a
District Youth Council.



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Acknowledgements

The Lancashire LINK would like to thank the young people from the District Youth Council and their leader for allowing us to attend their meeting and for their valuable comments.

Introduction

In February 2011, the NCB (National Children's Bureau) and VSS (Voluntary Sector Support) organised a seminar on *Involving Children and Young People in LINKs*. During this event, it was evident that, whilst some LINKs had taken a proactive stance in terms of engaging with children and young people, others had been less committed to work with this sector for a variety of reasons, chief amongst these being other priorities and lack of clarity over the role of the LINK in relation to children and young people.

A number of useful approaches for working with children and young people were shared, including linking in with schools and colleges and also working with youth councils and school councils. From this seminar, a clear message emerged about the importance of the LINK forging stronger relationships with children and young people.

Within Lancashire, the Lancashire LINK Board had already expressed a commitment towards ensuring children and young people's issues are covered, prior to this event. Following on from this, Board members and community engagement staff have begun creating links with Lancashire County Council's Children's Services Directorate, Children's Trusts, public health leads with responsibility for children and young people, and voluntary and third sector organisations.

In order to gain an insight into young people's experiences and perceptions of health care services, a group discussion was conducted with a group of young people from a District Youth Council in May 2011. Because of the sensitive nature of the issues that emerged, together with the need to maintain the confidentiality of the individuals involved, we have chosen not to identify the Youth Council concerned. However, the findings should be of interest to commissioners and providers from health and children's social care from across the county.

The Youth Council is made up of a group of young people aged 11-19 who are chosen as representatives of their community and meet weekly. They are frequently consulted on a range of issues.

The discussion took place during one of the meetings and, because of time constraints, lasted approximately 25 minutes. There were eight young people present, together with a member of staff. The young people were questioned about what they thought about health services in general and whether they felt services were response to the needs of children and young people.

A number of issues and themes emerged. These included:

- Communication: health professionals not talking to young people at their level, or not providing enough information during diagnosis or follow-up
- Linked to the above, attitudes of certain health professionals to young people: ie being too ready to dismiss medical issues raised by young people, on the basis that they are too young to experience a specific condition
- Young people feeling they are not always listened to – for example, when experiencing pain
- Professionals/services being rushed
- Services not being suitable for young people: for example young people having to share a hospital ward with older patients
- The impact of information technology, such as computer touch screens, in removing the interpersonal element from primary and dental care.

Consultation results: what young people said about services?

Communication

A major concern to the young people was the way they felt doctors and other health care professionals spoke to them. They felt professionals either 'talked down' to them or did not explain their diagnosis adequately, leaving the young people feeling patronised or bewildered.

In relation to his experience of visiting a GP, one boy commented:

They're sort of, if they know what age you are, they still talk to you as if you are about five. It's all like when they're trying to explain summat, they start drawing diagrams and start using simple words ... we can understand things, so it's just talk to us normally, like a normal adult at the right age.

A girl commented:

Sometimes, if you go in with your parents, they'll talk to your parents and then look at your parents, rather than look at you.

When asked how this made her feel, she replied:

Stupid. And it's like they're quick to diagnose things.

Another girl felt that health professionals are not always equipped to deal with the specific needs of adolescents when they begin visiting a GP/dentist independently of their parents or carers.

When you become a young adult your parents can't always take time out to take you to the doctor. They {health professionals} don't know enough to know how to talk to you when you are on your own ... so when you're a little girl and you go with your parents and they try explaining things with diagrams, that's fine. But when you're older, like because your parents can't go or something, it's like they don't know what to talk to you about. So if you raise an issue, it's 'oh, you'll be fine, I'll give you this'...

A boy added: *I would rather they explain something to me and I don't understand it rather than not explaining something to me at all. Then even if your parents aren't there you can go home and tell your parents and they can explain it to you.*

Attitudes of health professionals towards young people

Some of the young people described how they felt medical professionals are quick to dismiss issues raised by teenagers on the basis that they are likely 'to be too young' to experience a particular condition. One boy described how he was experiencing thirst and fatigue. Thinking he might be diabetic, he went to his GP.

I said 'Do you think I could be diabetic' and he said 'No, you're not, you're too young.' I said 'There's a few people in my family who are' and he said 'If you're not feeling better after Christmas come back to me'. So that was it.

The same boy was admitted to hospital after suffering from chest pains whilst at college. He was taken by ambulance to the A&E unit and then transferred to the cardiac unit, where tests ruled out a heart attack. However, he said the test results were never followed up afterwards by his GP, leaving him anxious and uncertain.

The hospital, they were good, because they arranged for all the tests to be carried out, but when those test results came back and went to the doctor, the doctors never followed it up, so I never heard anything back. And I still get them {chest pains}

I can't fault the cardiac unit but for them to send a letter to the doctor and the doctor to do nothing ... Cos I've got a concave chest as well and they said it might be structural as well, because that's putting pressure on my heart – and then they never followed that up at the doctor's. And I spoke to one doctor, a retired doctor, and he said there's operations you can have to help with a concave chest.

This boy's response indicates that he is still clearly worried about his condition and the lack of follow-up from his GP has exacerbated his anxiety. It illustrates the need for health professionals to provide follow-up advice and reassurance in order to allay anxiety, rather than appearing to dismiss concerns raised by young people as seemingly trivial.

Young people feeling they are not always heard

Another boy described how he went to his GP suffering from continuous pain and was referred to his local hospital. He felt that medical professionals did not understand how bad his pain was.

I kept saying 'It {the pain} is getting worse' and they {doctors} kept saying 'No it isn't' and I'm the one who can tell it's getting worse. It got to the point where I was spending nights in hospital in pain but you do get to the point where you eventually you get referred, like I'm now going to Alder Hey Children's Hospital – but it {referral} takes forever and they still can't say what's wrong with me now.

The boy felt medical professionals at his local hospital were dismissive of his condition because of his age.

It's like you're a child and you're nothing – you can't comment or anything. I'm like 'Well it's here' {the pain} and it's like 'Well no, the pain's not there.' Well it clearly is... and I'm spending nights in hospital and they say it's not getting worse.

This boy's experiences illustrate how he didn't feel listened to and felt distressed as a consequence, and this clearly had a disempowering impact. In contrast, he said his experiences at Alder Hey made him feel listened to and valued.

*I think local hospitals need to take a step from Alder Hey Hospital on how they are with children. Like they {staff at Alder Hey} don't look at parents when they ask a question, they look at **You** and ask what's wrong. They listen to you and start actually doing something about it.*

Another boy agreed.

Alder Hey, they were really good when I went there. But every time I go to ...{his local GP} they talk to your parents first, then they tell my mum and dad what's going on, and then you start to get worried about what's happening.

There was agreement within the group that, because it is a specialist children's hospital, Alder Hey Children's NHS Foundation Trust, values the needs and feelings of children and young people, and has staff who are able to offer reassurance and allay any feelings of anxiety. One boy commented:

Alder Hey are fantastic at dealing with children. I think, like, they {other hospitals} need to take a leaf out of their books about talking to children. You can't help queues, but once you are there, you are sat down, the nurse is always with you and you are straight to a doctor and he sits down and talks to you.

Another boy commented:

Alder Hey have got a fantastic overnight facility. I stayed there for a week and my mum slept there and I felt fine but if I went to a normal hospital I'd feel petrified to stay. But because your mum's there it's fine, you get comfort. At the time I was only young so you don't know what is going to happen to you.

These comments illustrate how Alder Hey Hospital, with its specialist facilities, is seen as being understanding and supportive of the needs of children and young people, and offering an approach that other hospitals and health professionals could learn from. This raises the issue of how hospital and primary care staff can be trained to communicate effectively and empathetically with children and young people.

Professionals/services being rushed

Some of the young people in the group described how they felt staff were sometimes rushed and didn't always have time to talk to them or explain procedures properly. They felt that the vital interpersonal aspect of a visit to the dentist or doctor was often missing.

One boy described how visits to the dentist were sometimes rushed.

It's not the waiting part, but when you go in {to the surgery} they just seem determined just to get you in quick and out, you're not even sure whether they've done a proper job or not. Having your braces done especially, they just race it. You're in there with your braces on, five minutes later you're out.

You have more of a feel that you should be there to be treated nicely... cos, they don't, like, sit down and talk to you about what you're going to have done, it's only like quickly 'We're doing this, is that OK?'

Another boy described how his arm has been in a plaster cast for nine weeks, despite being told, initially, that this would be for six weeks. During this time, the cast has been replaced four times. The hospital staff had told him that, because the fracture was in a difficult place, it would take six weeks to heal; however, he feels that it is taking longer for it to heal because of an ill-fitted cast. It is his belief that staff have contributed to the delay in healing by rushing through the process of applying the plaster cast. Although this cannot be substantiated, it gives rise to his *perception* that staff rushing through the process of applying a plaster cast has contributed to a delay in healing.

My experience is they {hospital staff} rush things and it's that that causes more damage...the hospital said it was an awkward bone that was fractured and it would get worse before it gets better but that it should be done in six weeks. So six weeks later I went in, got it taken off and x-rayed, and I've had three different casts on since then... it's keeping me out of work which I can't really afford to do.

Services not always suitable for young people

Some of the young people felt hospital wards don't cater for the needs of young people. They feel that neither children's wards nor adult wards are appropriate to their needs and, again, highlighted the example of Alder Hey Hospital where wards are specifically designed to cater for the needs of adolescents. They described how they felt uncomfortable at having to share a ward with older adults.

The impact of computer technology

The young people felt that new technology devices, such as computer touch screens, used when reporting for an appointment during a visit to a GP or dental surgery, were impersonal and resulted in the loss of the vital interaction with the receptionist.

One boy commented:

The trouble is now, with the dentist's and even the doctor's, you don't really see anyone when you go in any more. You press, tap, a touch screen computer. Both my dentist's and doctor have introduced the touch screen, so you don't even see someone {a receptionist}. Not seeing someone when you're in there just doesn't feel right. What you want to know when you're in there is about waiting times and things like that. You don't want to be greeted by a computer screen... it's the personal touch with people. But this just makes you feel like a number or something.

Discussion and ways forward

The results from this discussion indicate that young people have a number of concerns in relation to health services.

In order to create youth-friendly health services, the Government has launched the '*You're Welcome*' *Quality Criteria for Young People Friendly Health Services (DoH, 2011)*, to ensure health services are accessible and welcoming to young people. One of the standards relates to staff training, and recommends that all staff who are likely to come into contact with young people receive appropriate training on understanding, engaging and communicating with young people, including an awareness of what it feels like to be a teenager. Another standard identifies the need for healthcare providers to provide an age-appropriate environment.

The results of our discussion group interview indicate that:

- Young people want to be treated as young adults by health care professionals. They want their medical condition explained to them in simple, yet non-patronising language.
- They want to be treated as patients in their own right, with respect, and with comments directed to them and not to their parents.
- They want to feel listened to and assured their symptoms are being taken seriously, and are not dismissed on the basis that they are 'too young.'
- They want reassurance that their medical care is being delivered in a seamless way, including follow-up information being provided by their GP after discharge from hospital.
- They value the interpersonal aspects of health care and are concerned at the introduction of touch screens and the potential loss of interaction with receptionists and other health staff.
- They appreciate that health care staff can often be very busy, but they would value more time being given to procedures, such routine dental appointments, rather than feeling rushed.
- They would like Alder Hey Hospital to be used as a model of good practice when developing protocols in relation to communicating with young people, and in ensuring hospital wards are young people-friendly, and are not seen as daunting or intimidating.

Lack of time prevented a more detailed exploration of the healthcare environment and what young people would like to see in terms of hospital wards and GP premises in order to create a more welcoming environment. It would also have been useful to have looked at issues relating to specific aspects of healthcare relevant to young people – such as stop smoking services, sexual health services, child and adolescent mental health services (CAMHS); however, we were mindful of not wanting to overstay our welcome. We suggest that perhaps a further visit is needed to explore these issues, subject to the agreement of the Youth Council. Further group work could also be undertaken with other identified groups of young people with specific needs, for example young carers.

From this small-scale consultation, it would appear evident that healthcare staff require training on communicating and engaging with young people (in line with the *You're Welcome Quality Standards*). It is suggested that a programme of relevant training could be commissioned by the newly formed GP Consortia, possibly working collaboratively with Children's Trusts, alongside local programmes established to take the requirements of the *You're Welcome Quality Criteria for Young People Friendly Health Services* forward.

The findings from this consultation mirror those of the young people who took part in a national consultation on the NHS White Paper organised by the NCB and VSS (NCB and VSS, 2010). The results from this indicate that young people have a number of concerns about the NHS, including lack of age appropriate services, lack of privacy on wards and poor communication and listening skills of staff. From this, a number of recommendations have been made, including all NHS staff becoming trained to be young person friendly and able to communicate and engage with young people effectively.

In another recommendation, it is suggested that young people could lead independent teams of mystery shoppers to scrutinise services. The report also recommends that hospitals and community wards services should be created specifically for young people, in recognition of their distinctive needs, rather than having them grouped with children or adults.

The Lancashire LINK feels that training in communicating and engaging with young people should be recognised as a priority, and commissioned through the GP Consortia, perhaps working alongside Children's Trusts. We are aware that, as part of *You're Welcome*, young people in Lancashire have been trained as internal verifiers who are able to visit health-related settings to assess the extent to which they are young people friendly, and are also able to offer training to health professionals on how to communicate with young people. We feel that GPs and other health care professionals could benefit a great deal from being trained by those who are experts on adolescence – the young people themselves.

References

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