Consulted but not heard: a qualitative study of young people's views of their local health service

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Abstract

Objectives The objective of this study was to identify what children and young people in a health district in a large urban area experience as positive – and not so positive – about their local health services, in the light of a growing expectation that users play a more central role in the design and delivery of services.

Design A qualitative study incorporating a range of methods, including interviews, play techniques and a website.

Setting Schools, nurseries, community groups, in- and outpatient settings in an inner London health authority.

Participants Young people aged between 4 and 19 years, from community ($n = 92$) and clinical ($n = 57$) settings. This included 'hard-to-reach' children, including those leaving care, those in touch with the criminal justice system, asylum seekers, and those with learning disabilities.

Results Alongside planning and environment issues, young people particularly emphasized the impact of communication and relationships with staff on their experience of health services.

Discussion and conclusions Using a range of flexible and age-appropriate techniques, young people, even those as young as 4 or 5, are able to comment helpfully on their experiences of service provision. What children had to say is revealing but not astonishing to those working in the National Health Service (NHS). Clinicians and managers, to whom our findings were fed back, made this clear. If we have known for so long that the issues raised here are problems, why are we so poor at acting on this knowledge? The authors suggest four explanations.

Introduction

'Children, young people and families should be routinely involved in the planning and improvement of services'.¹

Children and teenagers are increasingly recognized alongside other National Health Service (NHS) users as active participants in their health-care, and stakeholders whose views

should be taken into account in the planning and delivery of services.²⁻⁴ The Children's National Service Framework includes a commitment to involving children and parents in choices about their services¹ and there have been calls for the special health needs of children to be acknowledged and represented at all levels of health policy.⁵

The work described below was carried out in an inner London health authority. The aim was to explore the views of children and young people on their health-care in general and the health services they receive. This paper focuses on what they saw as positive, what they felt needed changing, and what followed as a result of the consultation. The relationship between consultation and change touches on an issue at the heart of public involvement in the NHS. Unless we can get this right, efforts to promote good practice and transparency in public involvement in health services are likely to be viewed with scepticism, and the time donated by those consulted wasted.

Methods

The balance of power between researcher and researched, within any one study design, is a contentious issue.^{6,7} Dyson and Meagher suggest some questions it may be useful to ask in order to identify the best combination of respective parties' expertise – where participants are the experts in their own lives and experiences, and where researchers remain, for the most part, the experts in producing 'trustworthy' data delivered within the structures required by research contracts.⁸ We adopted an approach which involved asking ourselves which aspects of the research process we as researchers needed to maintain control over in order to ensure 'robust' findings delivered within the framework agreed with our funders, and which aspects we could throw open to young people to decide in order to facilitate their telling their story 'in their own terms'.⁹ A particular practical and ethical concern was to ensure that the consultation was not simply a paper exercise, but would

contribute to the development of more permanent and interactive structures for dialogue between young health service users and providers.

Our approach was as follows:

*Provision of a range of attractive and accessible information and consent materials,*¹⁰ developed from Alderson's¹¹ framework for deciding what children need to know in order to give meaningful consent to taking part in a research project.

Child-led decision-making on some aspects of the research project – for example, around the presence (or not) of staff or parents during groups and interviews and around the size and composition of discussion groups. Children and teenagers, in particular expert patients, who had long-term chronic health problems which brought them into frequent contact with health services, were consulted on the development of the research instruments.

Methods of data collection appropriate to participants' differing needs and skills – Sociologists¹² have described the importance of recognizing how children's competencies are different, although by no means inferior, to those of adults, and the importance of developing research practice accordingly. We used small discussion groups with pictures and photographs as prompts and toys for role-play with the youngest children; drawing, writing and modelling with older children; and games and group discussions with teenagers. Our age-based assumptions about children's competencies¹³ were challenged when some older children proved as enthusiastic as their younger peers about role-play with 'early years' toys. It quickly became apparent that other children, including some very young children, and particularly expert patients, were skilled in one-to-one discussion with adult researchers and that in these cases a conventional interview approach was most appropriate. In a special school for teenagers with learning disabilities, we were able to build on work the teacher had done with the class identifying a range of feelings, such as anger, embarrassment, happiness, sadness or fear, in order to explore with participants how

they felt when using health services. In busy settings, such as outpatient clinics, time with participants was limited and frequently interrupted and therefore we found short questionnaires the most appropriate approach. These were designed around the issues raised by participants in discussion groups.

We adopted an opt-out basis for parental consent in order to give the maximum number of children and young people the opportunity to decide for themselves whether or not they wanted to take part. Carers received a letter prior to the consultation informing them that it would be taking place and giving them the opportunity to request that their child not take part. Children and young people themselves decided to take part in the consultation on an opt-in basis. In clinical settings, where the subject matter was potentially more sensitive, parents of under 16 years were approached to give consent for their child's participation prior to carrying out interviews. No adult refused this.

Interviews and group discussions were recorded and transcribed. Researchers read the data independently for recurring themes, and differences in interpretation were resolved through discussion. Direct quotations from the interviews were identified to illustrate these themes.

New technologies offer new methods, and we developed a website¹⁴ as a tool for both data collection and feedback to young people. Once the site was active, flyers were sent to GPs and schools to encourage children and teenagers to complete the on-line questionnaire. The website remained a tool for dialogue between service providers and youth users beyond the end of the consultation period, and we encouraged young people to 'vote' on the priorities for change and other young people identified during the consultation.

Participants

We used a purposive sampling technique to ensure that we met with young people aged 4–19 years across a range of community and clinical settings. In *community settings* we met with

- children and young people in their nursery, school or youth club, approached via their teacher or youth worker,
- disabled young people in specialist schools, approached via their teacher,
- refugee/asylum seeking children, approached via their social worker,
- care leavers, approached via local social services and
- young people in contact with the police or otherwise identified as vulnerable by their key worker, approached via their teacher or key worker.

In *clinical settings* we met young people at four local hospitals. They were approached via their consultant or parent and interviewed in hospital wards, outpatients' waiting rooms or at home. We interviewed young people with both acute and chronic conditions and from general paediatric and specialist settings.

Results

We met 92 young people in community settings (see Table 1) and 57 young people in clinical settings in four local hospitals (see Table 2).

Over a third of participants were from minority ethnic backgrounds. We met 72 girls and 77 boys.

What is good about health services?

Young people described examples of good resourcing of waiting areas for young children and good general practice:

'When I was younger I used to have this really nice woman, you went into her surgery, she had like all toys like ... and she made it really fun so I didn't mind going to the doctor'. (Member of group 13–14-year-old young people)

'[My GP is] really kind ... and she really helps me all the time'. (Member of group of 13–14-year-old young people)

Many young people liked the health-care staff they came into contact with, and appreciated efforts to make their experiences of health services as good as they could be. Direct

Table 1 Young people in community settings

92 young people in community settings

11 under 5-year-olds in nurseries	17 children in primary school after-school clubs	14 children in secondary schools	50 'hard to reach' young people: 15 teenagers in contact with criminal justice system; 13 asylum seeking young people; 13 teenagers with learning disabilities; 9 teenagers leaving care
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Table 2 Young people in clinical settings

57 young people in clinical settings

25 one-to-one/small group interviews in hospital schools or wards	32 accompanied questionnaires completed in outpatients settings
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communication, sensitivity and the transforming effect of even the smallest acts of consideration by staff (not only health professionals) were all appreciated:

"Did he talk to you or to your mum?"

"He talks to both of us".

"Which do you prefer?"

Me! (Member of group of 6–8-year-old girls)

'[The nurses] are nice. They're kind. If they say "You're seven stone" and everyone says "Is that overweight?" they say "No, that's fine". They don't want to put people down in case they get upset'. (13-year-old young woman, expert patient)

'... the cleaners talk to you here'. (16-year-old young man, expert patient)

Young people in acute settings appeared to enjoy hospital schooling and input from youth and play therapists:

'It's nice in there 'cos the teachers – even if I can't get out of bed – they still come and give me work'. (13-year-old young women, expert patient)

'There is loads to do here ... they have after school things. There is this thing called cyber-youth where everyone of a certain age, over 11 or something like that ... There are other things like, trips out, they have like free tickets for people'. (16-year-old young man, expert patient)

Continuity of care was valued both in primary settings and by those with long-term conditions.

'She's really kind because I've got the same doctor as my mum and my mum's been with her since I was born'. (Member of group of 14-year-old young people)

'Can you think why you felt fine about [visiting the doctor?]

I'm very used to going and I know quite a lot of people there and [they are] used to seeing me and they're very nice'. (9-year-old boy, expert patient)

What is not so good about health services?

Issues which young people raised as problematic centred around planning, the environment, information, food, and, in particular, communication and relationships with staff. Planning problems included the need for improved continuity of care – particularly for looked after young people – and a need for support during transition to adult services.

'Usually I have like a senior house officer, they kind of go to different hospitals to build their experience. So I usually see one of them which is annoying because if it changes every time I come, by the time they've got to acquaint themselves with my notes [they have to leave]'. (18-year-old young woman, expert patient)

'He's brilliant. He really is a good doctor. He knows what he's talking about and he's thorough. It scares me to think that I'm going to have someone else because I've just started to get really used to him'. (15-year-old young woman, expert patient)

Other problematic issues included access to interpreting and translation services, and waiting times in A&E:

'I'd say the maximum time I've waited would be 5 h – that's because I broke my finger ... because it was minor. I was in pain, I was in a lot of pain'. (15-year-old young woman, expert patient)

Young people had a good deal to say about the need for age-appropriate facilities, for example, child-friendly places to wait in A&E:

'I think they should get their own children's room, like in the outpatients, 'cos it's like you see people that are really ill, that are lying on chairs, and they are taking up three, four chairs'. (13-year-old young woman)

Age-appropriate activities and resources in waiting areas were raised as problematic across settings:

'I've had to wait for a really, really long time, like 2 h in the doctor's, for my cough.
"Was there anything to do?"
No, just like baby things'. (Member of group of 6–8-year-old girls)

Suggested improvements included access to television, playstations, and magazines, for example, on IT, music or skateboarding. In clinical settings, although a few young people enjoyed sharing with those much younger than them, on the whole there was a consensus that sharing a ward with others more or less your own age was preferable to sharing across a wide age range:

'Because it's quite hard, it's all mixed you see. It's like young kids with old kids and it doesn't work'. (16-year-old young man, expert patient)

Accommodation of babies on wards with older children was repeatedly cited as problematic:

'There was a lady that had a baby ... and she came and said "the baby's trying to sleep" and that was a bit unfair ... that was my last day and I couldn't talk to [my friends] at all. I felt quite bad about that'. (13-year-old boy, expert patient)

All young people we met with who used wheelchairs had experienced access problems:

'[On] the old wards it's difficult to get to the bath ... and some of the doors are quite heavy. One of them is dangerous really, you know, those gliding doors'. (16-year-old young woman, expert patient)

Other environmental issues raised included the need for greater cleanliness and more privacy:

'It is quite dirty ... they clean the floor and stuff, but they don't clean the walls'. (15-year-old young man, expert patient)

"If you think about the first time you came here, was there anything that you were particularly concerned about?"

It's like having privacy, modesty and that kind of thing.

"And how has that worked out?"

Just, like, give up.

"So, would you have liked more privacy?"

Yeah'. (14-year-old young woman, expert patient)

The stereotype of poor hospital food was maintained by the children to whom we spoke. Some spoke of relatives bringing food in for them, and food inappropriate to their religious or cultural needs.

'I'm sure there is a lot more people like myself that would prefer a lot more than burgers and chips every dinner time. It's not like they have different meals for dinner and tea. They have the same ... they give you a menu and it's all the same stuff: chips, burgers, chicken nuggets, potato faces, salads'. (16-year-old young man, expert patient)

It was in the area of communication and relationships with staff that children and teenagers had most concerns. Listening was highly valued. For expert patients, this involved needing to 'teach' doctors:

'A lot of doctors I've met – not all of them, just a lot of them – if they've just kind of graduated they're the worst because they think they know everything. It's worst when they're trying to take my blood because I've got very small veins and I'm [saying]. "No, that's not going to work, you know, you may have got your PhD but I have been living in this body [with this illness] ... – listen to me!" and they don't really like that'. (18-year-old woman, expert patient)

Young people expressed the need for better information, in clear appropriate language:

'They gave me this little eye drop stuff and they did not tell me that it would sting my eyes. And I put them in my eyes and I was not happy at all. I just thought "Tosser"!'. (Member of group of 14–15-year-old young women)

'They come out with some long words man. They talk to my parents but even my parents don't understand.
'What does it take to be a nice doctor'? ...
Not all them long words'. (Members of group of 14–15-year-old young men)

They described the importance of professionals being aware of issues which may be sensitive – for example, knowing when not to ask about risk behaviours:

'My mum's beside me, [the doctor says] "Are you sexually active"? You're just like: my mum! Me and my mum! I don't wanna answer. It's like "Do you smoke, do you take drugs, are you an alcoholic"? You don't wanna answer to that in front of your mum!' (14-year-old young woman)

Young people with learning disabilities and their teachers described particular gaps in age-appropriate sensitive services. We were told that most young people described how visiting the doctor made them feel 'sad', 'embarrassed' or 'scared'. One young man said that he felt embarrassed:

'Because I had to lift my top.'
(Young man in group of 14–17-year-old teenagers with learning disabilities)

Repeatedly, young people identified the importance of being treated with courtesy and respect:

'The doctors weren't very [friendly]. They just came in. They didn't say "How are you" or anything. They just came in and said "Oh, we're going to operate here" and "I'll better stick this tube in your leg" or something'. (14-year-old young man)

Paradoxically, we found the group with some of the highest expectations (and the lowest opinion) of the health services to be young people at risk of the poorest health outcomes, including looked after children, and children in contact with the law.

'They don't talk to you. They do what they got to do and scruff you out the way ...
They think, especially kids like us, they think we're faking it. We're lying: "Just shut up and get on with it"'! (Group of 14–16-year-old looked after young people)

Where they raised these criticisms, older children and teenagers were also aware of origins of some of these issues in the pressurized environments in which staff operate:

'[Doctors should] cheer up. Just because they're underpaid it doesn't mean they have to take it out on us.
Put a smile on their faces! ...
I'm quite scared of doctors 'cos they're underpaid and they're grumpy'. (Group of 14-year-old young people)

Discussion

What children had to say is revealing, but we are aware that their observations do not necessarily provide dramatic insights to those working in children's services in the NHS. Clinicians and managers, to whom our findings were fed back, made this clear. This, in a sense, is a key finding. If practitioners and managers have known for so long that the issues raised here are problems, (and we have no reason to doubt this), why are we so poor at acting on this knowledge?

We believe that there are at least four plausible explanations:

- Children tend not to have the power which might enable them to exert the political or lobbying clout of other important user groups of health services such as women having babies, or HIV-positive men. Parents who might lobby on behalf of their children can be marginalized, persuaded that the most important thing they can do is fundraise, or may be concerned (not unrealistically) that they may be seen as trouble if they complain too vociferously. We were aware that active, solution-focussed parents might have their concerns treated seriously by frontline staff, but no one appeared to have the time or the responsibility to take suggestions to their conclusion.
- Disruptions in NHS structures, mergers and changes, often promoted as improving efficiency and reducing costs, result in considerable disruption of services,¹⁶ partly through a failure of organizational memory.

Between the completion of our work and the publication of our initial report, the health authority had been re-organized into a new strategic health authority, covering a larger area. In July 2003, this body called for children and young people to tell them about their use of health services and how things might be improved. They received only 44 replies, covering issues including 'not listening', the environment, food, cleanliness and waiting. We have no way of knowing whether this low-response rate was related to there having been a prior consultation on much the same subject and no reference was made to the earlier work. Further, with pressure to be strategic, it may be that there is so much concentration on the big picture that small-scale local improvements – quick wins in which a speedy response is made to common sense suggestions from young users – get lost. Meanwhile, in terms of accountability, Pauline Allen plausibly argues that downwards accountability is likely to be have the least attention paid to it in the short-term.¹⁷

- There is a very large agenda for change in the NHS.¹⁵ Consulting children and responding to what they say has not always been part of this. The patient involvement section of the NHS Plan did not specify 'children' and while children are people (and patients) too, not every trust takes this on board. At present, the routine Hospital Inpatient Surveys – now a requirement for all acute hospitals, only cover adults over the age of 16. The Children's National Service Framework (NSF) now articulates the importance of involving children, and the improvement of their services. Key issues identified in our study are similar to those set out in the NSF,¹ but these lag well behind other priorities. In the short- to medium-term, one can see why a focus on waiting times and cancer services (for instance) should be high on everyone's agenda. But in the longer term, failing to respond to young stakeholders is likely to undermine their willingness to play an active role in using, supporting and improving public services.

- There are few rewards for individual practitioners who improve their own service, surgery, ward or patch for young stakeholders, and no real disincentives to conducting business as usual for the less child-friendly practitioner or service.

Conclusions

Using a range of flexible and age-appropriate techniques, young people, even those aged 4 or 5 years, are able to comment helpfully on their experiences of service provision. The children and teenagers we spoke with were articulate in relating examples of good relationships with health professionals, good provision for younger children in waiting areas, and good general practice. They also identified the importance of improved planning and resourcing, for example, in relation to age-appropriate and accessible facilities. The pivotal role of good communication and relationships with staff was emphasized both within what young people said is good – and within what they said needs improving.

While methods for effective consultation of young people are improving,¹⁸ our ability to respond adequately lags behind and the pace of change is slow. What might make a difference?

In future, children will be surveyed (or whatever is age-appropriate) on a routine basis. From April 2004, Trusts will be expected to administer a parent survey – followed by efforts to seek children's views directly. There is an opportunity here for The Commission for Health Care Audit and Inspection (CHAI) to build inspection mechanisms that can assess the whole loop – from seeking views, planning changes involving children, making the changes, monitoring them and then seeking views on the changes. Incentives to act on what we learn from patients and users may be the only way to make sure that they are seen and heard.

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