CHILDREN AND YOUNG PEOPLE’S VIEWS
ON
HEALTH AND HEALTH SERVICES

A review of the evidence

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- There has been a large amount of consultation with children and young people and there is good knowledge on how they think services should be improved. While studies reveal very interesting information on specific issues, some consistent themes emerge. What is now needed is action to take notice of their suggestions and bring services more in line with what they would like.

- A listening culture within services themselves is an integral part of any meaningful attempt to consult children and young people about their health care.

- Communication is a key issue for children and young people, and they want all service providers (including reception staff) to be good at talking and listening to young people. They want to be treated with courtesy and respect, and for their views to be sought when decisions are being made about their health care. Children and young people would like to be offered choices in their health care and for it not to be assumed that 'parents know better'.

- Confidentiality is a major concern for young people using healthcare services. They seem to be particularly wary of GP services, including reception staff, in this respect.

- Health and well-being are often seen in broad and holistic terms by children and young people, who place a strong emphasis on feelings and emotions as well as positive relationships with friends and others. They recognise that their behaviour is powerfully influenced by how they feel.

- Most young people have a good understanding about healthy lifestyles, and they are able to identify what would help them live more healthily. Patterns of behaviour in relation to sexual health, drug and alcohol use and eating, in particular, need to be understood in the context of their feelings and emotions, and services planned accordingly.

- Children's and young people's accounts of healthy living place a strong emphasis on their environment, primarily their neighbourhood and school. These should be safe, friendly, enjoyable and supportive, and free from bullying and other forms of harassment.
Although most young people consider themselves to be healthy, many do have health and well-being concerns for which they may not be seeking help or support: stress is a particular concern for many teenagers. This is often linked to a poor understanding of what services exist or to feeling that the opening hours of services make them inaccessible.

There is general appreciation of drop-in services, especially if these assure confidentiality. If located outside school, young people want them to be accessible during out-of-school hours.

The physical environment in which all healthcare services are provided – for example, drop-in centres, GP surgeries, hospital waiting areas, and hospital wards – is important if children and young people are to feel comfortable. They want services to be welcoming and friendly, with age-appropriate things to do while they wait.

Children and young people who use hospital inpatient services would prefer to be treated alongside other young people of a similar age.

Those who use specialist health services often see themselves as experts on their condition and want practitioners to regard them as partners in their own health care.

It is clear that children and young people identify similar characteristics of good health services whatever their background or circumstances, but there are nevertheless some groups who may have greater contact with services as well as special needs eg. looked after children, or those with a disability or chronic illness. Services should be provided according to individual need as identified by young people themselves.
INTRODUCTION

Background

There is, nowadays, general consensus that children and young people should be consulted about their health and health needs, and that their views should be taken into account in the planning and development of health services. Following the ratification of the UN Convention on the Rights of the Child by the UK government in 1991, and particularly Article 12, which has encouraged and reinforced the movement towards greater involvement of children in decision-making, there has been an enormous amount of guidance and legislation culminating in the Children Act 2004. The five outcomes embodied in Every Child Matters, for instance, include ‘make a positive contribution’ which incorporates the notions of involvement and participation. The importance and significance of listening to young people, and taking their views into account, is also reflected in the fact that only recently has the first Minister for Children been appointed in England. Additionally, each nation in the UK now has a statutory Children’s commissioner: one of the main functions of this role is to listen to, represent, and respond to the views of children and young people.

Government departments have been charged with taking this participation agenda forward, and the Children’s and Young People’s Unit (CYPU, 2001) outlined how

The Government wants children and young people to have more opportunities to get involved in the design, provision and evaluation of policies and services that affect them or which they use.

The challenge is being met and there are now numerous demonstrations of how models of participation are being, and can be, implemented (eg. Kirby et al, 2003; Mason and Fattore, 2005) to be ‘meaningful, effective and sustainable’ (Sinclair, 2004). Participation has also become a key element of many new national frameworks for youth action (eg. Russell, 2005).

Initiatives in the field of health and health care are growing, and it is likely that the agenda has changed considerably since 1998 when Hart and Chesson argued that although children are major users of health services, they are rarely consulted as healthcare consumers. Their needs were, certainly at that time, given insufficient
priority by policy makers and health service professionals despite a recommendation by the British government’s health committee, in the previous year, that changes in attitudes were needed to encourage greater heed of children’s voices and views.

Among recent moves in this direction, the Royal College of Paediatrics and Child Health (2005) has developed a strategy to promote participation of children and young people in paediatric activity which, very aptly, draws on the findings from consultations with children and young people as well as members of the Royal College of Paediatrics and Child Health committees and RCPCH staff. It was also supported by a young person’s advisory group. And as part of the development of a single inspection framework following the Every Child Matters Green Paper, there is a commitment to the involvement of children in the inspection process. The Department of Health itself published Listening, Hearing and Responding, its action plan to involve children and young people, in June 2002 and has since updated this by describing key achievements and setting new and immediate priorities. Further government activity in the area of adolescent health is evident in the ‘You’re Welcome’ Quality Criteria for Young People that have been established to enable health services to become young people friendly, as well as in part of the Transforming Health Services strand, delivering Choosing Health.

There have also been important initiatives to seek young people’s views on these matters. One that is particularly relevant for this literature review is the Children’s Voices project from the Commission for Health Improvement (Boylan, 2004), which collected and organised feedback from children and young people about their experience and expectations of healthcare. This project arose from a request by CHI commissioners for information on children and young people’s views which could influence the development of future inspection methodologies. In summer 2003, CHI collected together reports providing young people’s views on health services, and put these onto a database with online search facilities. There was felt to be potential for this database to become a continuing resource, and it was agreed that CHAI, (now the Healthcare Commission) would take responsibility for the project when CHI was abolished. Another welcome development is the first Young Patients Survey, carried out in 2004 for the Healthcare Commission. This was a major survey, carried out in 150 NHS acute and specialist trusts, and gathering views from over 62,000 children and young people who had used these services.
These, and a range of other activities, attest to the current commitment to the consultation of children and young people in relation to their health and health services.

This review

The aim of this report is to document evidence that has emerged in recent years on children and young people’s views of health and health services. It addresses the why and how of consulting children, looks at young people’s views on health and well-being, their perceptions of healthy living and associated barriers, and examines what young people think about health services they have used and the provision they would like. The review makes no claim to include all relevant information in these areas.

Health, as considered throughout this review, is not defined simply as physical health but encompasses broader mental and emotional health as well as general well-being. In practice, however, no single view of health is adopted throughout the review as its meaning is somewhat dependent on the area under consideration. It is, for instance, taken to mean what young people say it means when discussed from their perspectives in the section on ‘Health and healthy living’. And, in other sections, health may be defined by those carrying out studies and consultations, or according to types of health services and provision.

The remit of this review, particularly if a broad definition of health is taken, puts few boundaries on what should or should not be included. This report has, however, necessarily restricted itself, in the main, to consideration of physical and emotional health and the services for children and young people in these areas. Many other aspects of young people’s lives, such as bullying and other stressful events, are implicated in their health and well-being. Reference has been made to these when they arise from enquiry into young people’s views of health and health services, but they have not been covered as topics in their own right. Similarly, the literature on aspects of ‘healthy living’ (such as smoking, diet and so on) has been discussed selectively in relation to young people’s views on how these behaviours relate to their health and well-being more generally.
How the review was conducted

A wide range of documentation was examined for this review, and an essential criterion for materials consulted was that they included young people’s perspectives on health, healthy living or health services. All age groups up to approximately 20 years were considered. The majority of the information reviewed relates to the UK, although a few citations fall outside this geographical boundary.

Relevant information and research literature was identified using a number of complementary search strategies, determined in consultation between the review team. Data sources consulted included:

- NCB Library and Information Service, the Kings Fund Library, other libraries, publication lists, websites, and online databases using suitable keywords to identify literature, research reports, surveys of young people, and other documentation with information relevant to the issues of health and health care
- the work and documentation of relevant government and non-governmental agencies
- statistical sources providing demographic information on young people and their environments
- an enquiry was posted on the email list for the Children's and Young People's Participation Learning Network and drew eleven helpful replies
- consultation with colleagues, professionals and others
- general internet searches for additional information in these areas
CONSULTING CHILDREN AND YOUNG PEOPLE

There is a strong case for involving children and young people in their health care. They have their own views, are able to speak for themselves, and what they say often differs from what other adults say on their behalf. Moreover, almost any child can participate in this way, whatever their age, culture or educational needs. All the same, children and young people do need to be directly consulted if they are to express their views, and they need to be motivated to do so by knowing that what they say will be heeded.

To date there is only limited evidence that consultation makes a difference to outcomes for children. It is suggested that more attention is paid to the assessment and evaluation of children’s services from this perspective – both to encourage consultation with young people, and to convince young people themselves that it is worthwhile saying what they think.

The rationale

As Moules (2002) points out, there is every justification for involving children and young people in determining their health care. Government policy and guidance documents make this clear through emphasizing their role as active consumers of health services who should play a part in decision-making that affects their lives.

It is, furthermore, increasingly apparent that almost all children, whatever their age and circumstances, can provide valuable perceptions that can improve clinic care (Chesney et al, 2005). Curtis et al (2004) demonstrated that even children as young as four or five can make helpful comments about their experiences of local health services, provided that a range of flexible and age-appropriate techniques are used. Dickins (2004) has provided guidance for early years workers on consulting young children together with a range of techniques that can be used to help them express their views and make choices. Elliott and Watson (1997) have further shown that very young children say they would like to be involved in these ways.
The case for asking children themselves for their views is strengthened by unequivocal demonstration that children’s views do not always mirror those of their parents and other adults. This is true in relation to both health and health services.

Meade et al (2001), for example, have pointed to the importance of distinguishing between children’s and parents’ reports of illness. They looked at the impact of negative life events on children's health status, and found that a child's report of somatic symptoms was only minimally related to that of his or her parents. It was also found that children skilled at communicating their feelings have parents who report higher levels of health problems for the child. This suggests that clinicians should be aware that parents' reports are a function of how well the child communicates, and also indicates that the views of both generations should be taken into account.

Young people may also differ from their parents in their views of services. In an American study, Chesney et al (2005) compared satisfaction with outpatient care in 115 families and found that it was rated much more positively by parents than by their children. There was also a considerable difference in the comments made by the two groups when asked in a more open-ended way for their views on provision. The authors concluded that parents cannot generally speak for their children on matters of health care, and that young people themselves can provide valuable perceptions on their own care. Hart and Chesson (1998) also reported how children's concepts of hospital care and illness differ greatly from those of adults.

Much the same conclusions have arisen from investigations of young people with special needs. McConkey and Smyth (2003) found that parents’ views about hazards faced by their teenage children with severe learning difficulties were somewhat different from those perceived by the children themselves: whereas parents stressed the amount of care and supervision required, and young people’s vulnerability to hazards such as crossing roads and being taken advantage of sexually, the young people felt verbal abuse and bullying from peers was a bigger risk. In relation to services, things disabled children say they do not like about hospitals (eg. boredom and missing friends) are rather different from those their parents would select (Chapman et al, 2000). Somewhat similarly, Mitchell and Sloper (2003) reported a partial mismatch between disabled children’s and parents’ priorities for, and experiences of, health and social care services. In particular, having opportunities to make choices about services was a core priority for children but not for their parents.
More broadly, young people’s views of health and health issues may not accord with those of the professionals they are in contact with. This was demonstrated by Percy-Smith et al (2003) who reported how young people saw issues as messy and interconnected and, unlike the professionals, focused on relationships rather than on services. They saw medical problems as having their roots in social problems and so were interested in solutions to social problems. In particular, they emphasised how young people feel in themselves, relationships with others, their ability to thrive in the world, and the quality of their neighbourhood.

The conclusion from such studies is that it is important to take children’s and young people’s views into account alongside those of their parents and carers and health professionals. They often provide a different perspective and young people are likely to know best about their own needs and feelings.

**Children’s views on the consultation process**

Children and young people do not all have the same views on how they should be consulted about their health and health services, and indeed not all wish to be consulted to the same degree. Tailoring methods to the children and young people in question is important (Lightfoot and Sloper, 2002b) and there is no single ‘right’ way to consult young patients. Different methods suit different people (written methods do not work for people who cannot read or write well, or who do not like writing; shy people do not like being consulted in a group) and, if a choice of methods is offered, more patients may be happy to take part.

Although the literature is not extensive, some key principles are emerging from direct work with young people on how to involve them in consultations about health service provision.

Based on work with 13 to 20 year-olds, Lightfoot and Sloper (2002a) developed guidelines on how to involve young people in hospital service development. They argue that understanding motivation is important in appreciating how particular services might appeal to patients. From their own work, they report that young people are motivated by:
• wanting to make things better for other young people
• the opportunity to let staff know what needs to change
• feeling confident that something will happen as a result
• wanting to give something back to the staff
• a challenge, a chance to do something different
• feeling valued by having their opinions heard
• having something interesting to do in hospital – especially if it sounds like fun

In a separate exercise, and following consultation with young people in five locations, Laws (1998) identified 10 key principles for consulting young people using mental health services. These are likely to be applicable more broadly:¹

- Recognise young people’s competence
- Allow enough time to build up trust and to carry out the work
- Be flexible about the process you follow
- Involve people who are good at communicating with young people
- Work with existing services
- Ensure that you have the support you need
- Ensure that the young people’s views are heard
- Set up an advisory group for the project
- Engage other agencies with your project
- Sustain this work

**Does consultation make a difference?**

One of the fundamental reasons for soliciting children’s and young people’s views on their health and experiences of health services is the expectation that this will, in some way, lead to improved services that better meet young people’s needs. Is there any evidence that this is indeed the case?

¹ The children’s mental health charity, YoungMinds, has also produced a guide for practitioners which includes a checklist for staff to consider when developing user participation schemes, and describes different models and benefits of children’s participation, and, *Putting Participation into Practice: a guide for practitioners working in services to promote the mental health and wellbeing of children and young people*. (2005)
To investigate this question, Sloper and Lightfoot (2003) carried out a postal survey of all 99 health authorities and 410 NHS trusts in England to ask about the extent and nature of involvement by physically disabled or chronically ill children and young people in local health service development. 76 per cent of health authorities and 59 per cent of Trusts responded, and 27 initiatives which consulted chronically ill or disabled children and young people about service development were identified. Over half were carried out in partnership between health services and other agencies, usually local authorities and/or voluntary organisations. There was a variety of approaches to consultation, including child-friendly methods such as drawing, drama and making a video. Seventeen initiatives reported that children's involvement had resulted in service changes, but only 11 went beyond consultation to involve children and young people in decision-making about service development. Only a third of the organisations had someone with designated responsibility for children's involvement.

From this and other findings, Cavet and Sloper (2004) conclude that there is only limited evidence that children and young people's involvement in public decision-making leads to more appropriate services. It is likely that they benefit in terms of personal development, and from staff and organisations becoming more aware of their views, but there is little conclusive indication that their health and health care needs are better met as a result.

There are, of course, instances in which the impact of children’s views has been demonstrated. Willow (1997) cites three examples: children successfully involved in designing a new hospital; children having an influence through their opinions about hospital stays; and a health project in which children encouraged hospitals to change practice after their complaints about the poor choice of food and noisy wards at night and a request for duvets rather than blankets. In addition, Tisdall and Davis (2004) outline how participation work with children can be translated from principle to effective practice. They charted how young people taking part in a consultation project on consulting disabled children and young people were influential in increasing the resources of the participating groups.

Nonetheless, despite these illustrations, there has been little demonstration of how young people have actually been able to effect changes in outcomes (in the short- and the longer-term) for children’s health and well-being (Cavet and Sloper, 2004). Moules (2002), accordingly, has made a call for much greater involvement of children and young people in clinical audit. Although the Department of Health (1994) requires
organisations to develop effective ways of involving consumers in clinical audit in order to contribute to the assessment and evaluation of services, there has been limited involvement of young people in this way. Where young people have contributed to clinical audit, this has typically been through one-off surveys rather than more meaningful participation.

**Children with special educational needs**

Consulting children and young people with special educational needs may require special considerations. There is a considerable amount of guidance in this area, much of which is about developing approaches suitable to the needs of children with learning difficulties and autistic spectrum disorders, such as through the use of cameras and Talking Mats (Germain, 2004), sign language and visual techniques (Kirkbride, 1999), and other approaches (Beresford, 2004; Porter and Lewis, 2004; Ware, 2004). Very often methods and techniques are tailored to the requirements of individual children and a range of complementary strategies may need to be employed.

The problem for some children with special needs may be more about access to opportunities to provide their views than about communication difficulties. Abrams (2002) demonstrated how this could be reduced by seeking young people’s views on the Scottish organisation Playback, that works with and for children and young people with physical disabilities and their families, and organises and assists their participation in conferences, consultations and the writing of articles. Similarly, Miller (2003) reports on a project run by the Children's Society to give disabled children an opportunity to tell the government and professionals what they want and need, and why they want to be involved in planning services.

**Effective consultation with young people**

Children and young people themselves have often informed guidance on how they can most effectively be consulted. A report from the London NHS, and guidance to CAMHS from Young Minds, in conjunction with the Young People’s Health Network, is illustrative. More specifically, Carney et al (2003) report on a study of 213 school-aged children in paediatric wards at two district general hospitals. They suggest that
a verbal structured questionnaire is the most efficient method for obtaining children’s views in these settings, but that a visual structured questionnaire was the only method which recognized the children’s sequence of feelings before, during and after hospitalization.

Indeed, the techniques used to gain views will determine the success of a consultation exercise. Chapman et al (2000) examined suitable approaches with children and offered children choices about whether to be involved and how they wanted to record their views. Participatory games and activities were devised to ensure that the consultation was fun for the children as well as useful for the adults. Work with older children and young people was carried out in groups or through the use of questionnaires. Five main approaches were used with 5 to 11 year-olds, all of which were found to be useful: Persona dolls; a ‘keyword’ task allowing children to explore the meaning of words from their own perspective; using speech bubble messages to complete sentences indicating their views on health (eg. I like the doctor because…); agreeing or disagreeing with statements; and drawing pictures of health spaces from the position of what they are currently like or how they should ideally be. There are also examples of effective pieces of work engaging young people on health issues by using theatre (Jackson, 2003) and art (Gaze, 1997).

An increasingly popular strategy is to involve young people as researchers to find out other young people’s views. Involve (Kirby, 2004) worked with a group of young people, as well as older adults who have been involved in research, to develop a guide containing information on the benefits of involving young people, when and how to involve them, and the power issues that can arise in using young researchers.

Communication is also key. Callahan et al (2005) involved children, young people and their families in training programmes and service design to identify the characteristics of good communication between children, their families and health professionals. They also outline the benefits, barriers and challenges of such communication and participation, and examine how some barriers can be overcome. Emerson et al (2000a) report on the findings from a participation project on young people’s views about principles and processes for engaging children and young people in consultations.

A number of key principles emerge from reports, and relate among other things, to the timing of consultation as well as the need to treat all children and young people
individually, and to ensure their willingness to be involved (eg. Lightfoot and Sloper, 2002a; Warwick et al, 1998; Dickins, 2004). Cavet and Sloper (2004) outline how work with young people suggests that good practice includes:

• a listening culture among staff
• clarity – about purpose, objectives and parameters for decision-making, and about planning, outcomes and limitations (when young people are recruited they need clear information about what to expect, and honesty about the degree of power-sharing available)
• flexibility – the use of a wide range of methods and approaches
• adequate resources
• skills development and training for staff and participating children and young people
• inclusion of marginalized groups
• feedback and evaluation
HEALTH AND HEALTHY LIVING: WHAT CHILDREN AND YOUNG PEOPLE THINK

Young people define health holistically, and place strong emphasis on their relationships and emotions and how they feel. Health is not simply about being physically well or unwell. The environment, too, is seen as critical through its influence on opportunities for healthy lifestyles and its impact on emotional well-being. Children and young people have a good understanding of what is considered healthy and unhealthy but nonetheless suggest that the environment, and their way of life, does not always favour healthy options.

The meaning of health

It is apparent that young people do not view health as simply not being ill in a physical, or mental, sense. They see it as a reflection of their lifestyle and well-being more generally, and place a strong emphasis on their feelings. Their health in this sense is strongly influenced by their relationships and friendships, and is also affected by the environment – the local neighbourhood, as well as schools and other settings - in which they live.

There have been a number of studies asking children for their views and understanding of health (Emerson et al, 2000; Chapman et al, 2000; Stockdale and Katz, 2002; Stansfeld et al, 2003), and it is clear that even fairly young children are well able to provide perspectives. The majority of investigations suggest a close link between healthy living and perceptions of health. In one study, for example, 11 to 24 year olds mentioned a balanced diet, taking exercise, and not smoking or drinking, as important for their health (Chapman, et al, 2000). They also seem well able to articulate the dominant Western health messages (Burrows and Wright, 2004).

What comes through particularly strongly from young people is a holistic view of health. Young researchers examining fellow pupils’ experiences of ‘health’ services demonstrated, for example, how young people thought that ‘health’ should be regarded as everything to do with keeping well and not just about being ill (Cant et al, 1999). The participants saw positive actions to make their lives more healthy as important as visits to the doctor or hospital. These included providing a balanced diet
at school as well as good advice, directed at young people, on how to achieve healthy lifestyles.

Findings from a peer research project investigating understandings of health (Percy-Smith et al., 2003) provide further illustration. This study had 2 elements: youth peer research involving 11 peer researchers from different communities who ran seven peer research projects in different settings; and a Knowledge Café event involving 62 young people and 31 professionals. Young people did not provide straightforward definitions of health and instead described how different elements of their lives were interconnected and important. On the whole, they placed a strong emphasis on relationships and stressed that health was about how young people feel about themselves, their relationships with others, their ability to thrive in the world, and the quality of their neighbourhood. Body image and the pressure to have cosmetic surgery, and a lack of facilities and places to go, were also mentioned as important contributory factors. The authors conclude that broad ranging health needs of the majority of young people, rooted in the context of their everyday lives, experiences and relationships, are not being understood as the necessary foundation for constructing effective local health policies.

Marks et al. (2004) have suggested that concepts of health and well-being incorporate more than satisfaction, and that a second dimension of ‘personal development’ is relevant too. Questionnaires were completed by a thousand children and young people from 7 to 19 years in Nottingham: just over half the respondents scored well on both life satisfaction and personal development scales, while one in eight scored poorly on both. Well-being in this sense appeared to decrease as young people got older. The authors suggest that the ability to cope flexibly and creatively with life’s challenges is related to long-term health outcomes, and that personal development is a key contributory factor.

The lack of a straightforward relationship between health and well-being has emerged from studies of selected groups of children. Monaghan and Broad (2003) reported semi-structured interviews and group sessions with 102 young people aged between 16 and 25 years and attached to three projects for young people facing social exclusion. Over half these young people had spent some time in the care of the local authority, the majority were on low incomes, most had difficult family relationships, about half had left school before the legal minimum age, and almost all lived alone and/or in unsatisfactory accommodation. When asked about their health,
two-thirds said it was ‘good’ or ‘ok’, and the rest said ‘not good’, ‘poor’ or ‘bad’.
However, when asked if they felt healthy, half said no. About one in four of the young people in the survey said that smoking affected their health, and others said that a lack of money, stress, or living in a hostel, was contributory. The authors suggested this showed the importance the young people attached to their feelings and emotions in defining their personal well-being.

Anderson et al (2004a) looked at the perceptions of health among 6 to 12 year-olds in foster care. Despite their young age, the children were broadly aware of what constitutes and promotes good health. In contrast they gave a range of definitions of mental illness.

Not surprisingly, younger children may be less inclined than teenagers and other young people to define health in such overtly holistic terms. For example, five to 11 year-olds, who took part in a study to provide a snapshot of issues children and young people saw as important in relation to health and health services (Chapman et al, 2000), mainly defined health in terms of a good diet, enough exercise and rest, and good hygiene (including dental hygiene). Some, however, also included terms relating to emotions and mental health – eg. ‘feelings’, ‘sad’ – in their general definitions. Nonetheless, evidence from the Children’s Rights Director’s consultation with children aged up to 12 on the five outcomes in the government’s Every Child Matters agenda, suggests that when asked what things are important to children, even younger children tend to think holistically: family, friends, fun, respect, and being happy were among the most common suggestions (Morgan, 2005).

In general, there is less consistency in young people’s descriptions of mental health than in their descriptions of physical health – even if there is a link between the two. In the evidence reviewed by Morgan, for instance, important health issues included stress – for example, young people feeling at breaking point, or having no-one to turn to, when faced by serious problems such as child abuse. Monaghan and Broad (2003) also reported that the young people in their study defined mental health problems in a range of different ways.

Most of the studies reported so far have looked at perceptions of health among children without significant health problems or special needs. Others, however, have examined the reality of health for young people with more specific concerns. Rushforth (1999), for example, reviewed the evidence to address the issue of
hospitalised children’s understanding of health and illness. She also examined what they thought about death. She argued that it is important to know what children think and understand when deciding whether or not they are competent to make decisions about their own treatment.

A variety of experiences have been recorded from young people’s perspectives in relation to conditions ranging from acquired brain injury (Heary et al, 2003), epilepsy (Ronen et al, 1999), blindness and partial sight (Cole-Hamilton and Vale, 2000), cancer (Bearison, 1991), chronic disease (Schmidt et al, 2003), diabetes (Datta, 2003), cerebral palsy (Waters et al, 2005), broader groups of disabled children (Connors and Stalker, 2003), and young people using assisted ventilation (Noyes, 1999). The impact of the illness or condition on the child’s life, and its implications for quality of life, are among the issues that have been examined.

A few studies of non-disabled children’s views on disability have also been reported, either from the perspectives of siblings (Stalker and Connors, 2004) or among more representative groups of young people (Smith and Williams, 2001; 2005). The purpose of some such studies has been to explore, developmentally, the understanding of causation and control in disability.

Do young people regard themselves as healthy and leading healthy lives?

The literature on children’s and young people’s views about their own health and healthy living presents a complicated picture. While most children and young people appear ready to say they are in good health, a number of qualitative studies suggest that many may nonetheless have significant concerns about their health and their ability to live healthily. Stress, in particular, appears to be a major factor in the lives of many young people.

More than 8,000 children aged 0 to 15 were interviewed (for children under 13, a parent or guardian answered questions on the child’s behalf with the child present) for the 2002 National Health Survey, in addition to more than 3,500 young adults aged 16 to 24. The overwhelming majority of children and young people said their health was good – even though a significant minority identified a longstanding health problem of some sort. Children aged 15 or under were more likely than the young
adults to report their general health as either good or very good (93% of boys and girls vs 87% of young men and 84% of young women). Boys (24%) were more likely to report a longstanding illness than girls (20%), but this difference was not found for the young adults (25% of males and 26% of females). Consistent with other findings, there was a link between better reported health and higher household income.

A survey of almost 3,000 children across six secondary schools in two areas of England produced broadly similar findings (Madge and Franklin, 2003). When asked to describe their health, 16% said it was excellent, 41% very good, and 40% good. Only 3% described their health as poor. Just over a quarter (27%) reported a medical problem or disability: asthma was by far the most common condition mentioned (411 pupils), followed by dyslexia (91), eczema (48), hay fever (42), migraine (16), diabetes (13), ADHD and epilepsy (11 each), and visual impairment (10).

Lower rates of health were reported by 2,800 11 to 14 year-old young people from 30 schools in East London (Stansfeld et al, 2003). Among this sample, most of whom were from black and minority ethnic backgrounds, 75% of boys and 72% of girls said their health was either very good or good. Furthermore, most of the adolescents expressed concerns about their health: for boys this was most likely to be about fitness, and for girls about weight. In a survey of 2,000 young people in public care, one in eight reported a disability or long-term health problem that affected their daily life (Shaw, 1998).

It is evident that, even if they say their health is good, many young people are experiencing significant problems. Many put a great emphasis on relationships, feelings and emotions. A number of qualitative studies suggest that stress in particular is a problem for many young people in their teens (Chapman et al, 2000; Kings Fund, 2000; Healey, 2002; Percy-Smith et al, 2003), with bullying playing a major role (Healey, 2002). It appears from the literature more generally that stress among young people is caused by many, and often inter-connected, circumstances that can include bullying, exam pressure, pressure from families, concerns about body image, peer pressure, and a lack of emotional support. The top worries among over one thousand young people in Waltham Forest and Redbridge were stress, followed by eating badly and not exercising, depression, body size, alcohol and having a worrying lifestyle, and smoking (Stockdale and Katz, 2002).
The impact of the environment

Children’s and young people’s accounts of their health and healthy living emphasise the role of the environment, whether at home or school, or in their neighbourhoods. Considerations such as cleanliness and safety are important, but so too are facilities, friendliness and general ‘ethos’.

Schools

Schools have been the focus of several studies. Mayall (1996), for example, drew on data from a large-scale survey of children, as well as six case studies, to investigate children’s health at primary school. She looked at aspects such as the buildings and lavatories, opportunities for a nutritious diet and exercise, relationships at school, and provision for care if children became ill. Based on what young people said, Mayall challenged the common designation of children as objects of the education system, and instead proposed that they are young people striving to maintain their well-being in a service under siege.

Vernon et al (2003) also explored the issue of school lavatories with primary school age children in England and Sweden. In both countries they found school toilets unpleasant, dirty, smelly, and frightening and a place where bullying occurred, and many children avoided using them (62% of boys and 35% of girls in the UK site and 28% of boys and girls in the Swedish site). The authors conclude that European standards are needed for school toilets in order to prevent children developing problems such as constipation, urinary tract infections and incontinence.

Healey (2002) found that many young people highlight the link between the school environment and their ability to learn. Basic facilities (such as lockers) and cleanliness (including and clean toilets) are strong concerns, but the less tangible ‘feel’ of a school – including friendliness, being noticed as an individual, and respect for cultural diversity – are also seen as critical. Young people tend to link school environment with both emotional well-being and learning. Nine out of ten children saw after-school facilities as an important component of a healthy school.
**Other settings**

Supported housing was the focus of one consultation about healthy living with four young people (Lewis, 2004). While participants shared the views of young people everywhere about the kinds of services they appreciated, and the importance of friendships and ‘fitting in’ for healthy lifestyles, they also identified the particular constraints present in their day-to-day environment. In particular they pointed to inadequate cooking facilities, lack of access to sports facilities, and the pressures in hostels to gain acceptance by getting involved in harmful patterns of behaviour. Ideas to improve their health and well-being included more outings, more group activities, internet access, a house phone, double-glazed windows, and new books for the library.

The role of lifestyle and the environment on health was also examined in a study of young people in custody (Lewis, 2005), and was in this instance found to have positive aspects. While these young people experienced a high level and range of needs, many explained how reception into custody had provided them with opportunities to improve some aspects of their health and well-being. It was a chance for those with chaotic lifestyles to settle into a routine, stop drinking and taking drugs, access healthcare services, start exercising, and fill gaps in their personal, social and health education. The physical and social fabric of the prison environment also had a crucial impact on their health and well-being as it was seen as an indication of their value. Young people identified the importance of a bright and comfortable physical environment and suggested that buildings should be designed to feel as open and unimposing as possible. Many suggested that their ‘pads should be more homely’ as this would help them feel more settled, less home sick, and more able to cope. Another study of the health and health needs of young offenders has provided complementary messages (Anderson et al, 2004b). Interestingly, this illustrated how perceptions of mental illness can range between stigma, aggression, lack of coping, previous experiences, and physical ill-health.

**Neighbourhoods and the wider environment**

Between 1998 and 2002, young people under 19 years took part in the Imagine London project which was designed to gather young Londoners’ views on how London could be made a healthier city (Kings Fund, 2000). These young people said
that healthy living depended on the environment and their access to sports, social and leisure facilities. Many also identified pollution as a direct health concern, at least in urban environments.

Morrow (2000; 2001) examined environmental issues and also explored the usefulness of Putnam’s (1993) concept of ‘social capital’ in relation to young people's health and well-being. She warns that young people are not a homogeneous category, and that gender, ethnic background, socio-economic status and age all need to be taken into account. She illustrated this from her own study by showing, for example, how girls felt less safe in their neighbourhood than boys, that young people from minority ethnic backgrounds were alone in reporting experiences of racial harassment, and how younger children wanted more places to play safely while older teenagers wanted places where they could socialise.

It is perhaps worth noting that most of the qualitative studies that look at children and young people’s perceptions of health in detail appear to be based predominantly on the views of young people living in cities or other urban environments. It is possible that the views of children and young people living in other situations may be different in some respects. This was certainly suggested by a report from the Health Development Agency (2002) that pointed out how young people’s health needs can be marginalised within rural areas. This conclusion was based on the views of 327 young people in Years 9 to 11 solicited in both school and non-school settings in an East Devon location. Young people’s main concerns seemed to relate to their mental well-being, and particularly around peer and family relationships, self-esteem, sexual health, and information and advice on drugs. Anecdotal evidence suggested these young people often did not use mainstream health provision as they were worried about confidentiality issues and as the services were often difficult to access. This project led to the establishment of a multi-agency drop-in open during school lunchtimes and other convenient times, and there was some initial indication that this was well received.

**Health knowledge and health behaviour**

Even though most young people regard themselves as healthy, they do not necessarily say they lead healthy lifestyles or live in particularly healthy
environments. Only 17 per cent of the young people who took part in a peer-led research project in Hounslow thought they lived in a ‘healthy society’. Of the rest, 41% said they lived in an unhealthy society, and 42% were not sure (Percy-Smith et al, 2003).

Shucksmith and Spratt (2002) reviewed qualitative research undertaken with young people between 11 and 25 years over the previous five years or so, and throw some light on the links between health and healthy living. They conclude that, even though young people tend to have good knowledge about how to maintain their health, they do not always act on this information. Importantly, it seems that the social context in which young people live is critical in determining their health behaviour in practice. The authors also conclude that young people’s health behaviour is often determined by a wish to act autonomously in reaction to the constraint and surveillance they often feel. Sometimes risky health behaviour can be a way of experimenting with a new ‘identity’.

Paradoxically, moreover, one health problem may lead to another. Thus Percy-Smith et al (2003) illustrated how young people may resort to smoking, drugs and alcohol to cope with stress. Their ability to cope with pressure from school can also affect their confidence and self-esteem.

There is considerable evidence to illustrate how young people’s knowledge about healthy living is, for a range of reasons, not necessarily reflected in their behaviour. This is examined below in relation to: diet and nutrition; obesity and eating disorders; physical exercise; alcohol, drugs and volatile substances; smoking; and sexual health.

**Diet and nutrition**

The evidence on children’s diet and nutrition suggests that even if children and young people have a reasonably sophisticated knowledge of what constitutes healthy eating, they will not necessarily follow a healthy diet. For many, this is not a priority in their day-to-day lives.
Unsurprisingly, it has been suggested that children’s understanding about food and nutrition may be influenced by personal factors including age. Hart et al (2002) carried out a study with more than a hundred primary school children (ages 7 to 11) in which issues such as parental food rules, children’s perceptions of good and bad foods, links between diet and disease, and food groupings, were discussed. First, gender and socio-economic status made a difference to parental control and children’s nutritional knowledge. Second, it seemed that cognitive development also played an important role in influencing children’s conceptualisations of food groupings and their understanding of the nutrients associated with different foods, and the health implications. It was suggested that primary school children may be most influenced by messages about healthy eating if these are appropriate to their cognitive level and, possibly, targeted separately at girls and boys.

Nutritional knowledge does not always mean healthy eating. An American study involving more than 200 adolescents in three high schools found the young people had a ‘significant amount’ of knowledge about healthy foods and believed healthy eating to involve moderation, balance and variety (Croll et al, 2001). Nevertheless, they found it hard to follow healthy eating recommendations and often consumed foods they thought were unhealthy. Barriers to eating healthily included a lack of time, limited availability of healthy food in schools, and a general lack of concern about following healthy eating recommendations.

A study of 106 11 to 12 year-olds identified taste, food appearance, filling power, time/effort, cost, availability, risk, rebellion, and body image or weight concerns, as barriers to healthy eating (McKinley et al, 2005). While there was some mention of balance in the group discussions, in practice children categorised food as either good or bad, healthy or unhealthy. The study also suggests different motives for diet between the sexes: girls tended to focus mainly on their appearance when deciding what to eat, while boys appeared to be more influenced by the impact on their sporting activities.

Another real barrier to dietary choice is the food on offer to children in the settings in which they live. School meals, for instance, are a frequent source of discontent for many children and young people. Complaints include poor quality, high cost, limited choice and a failure to cater for special dietary requirements (Healey, 2002). Ludvigsen and Sharma (2004) interviewed 174 children and young people (four year-
olds at nursery schools; ten year-olds at primary schools; and 15 year-olds at secondary schools) and looked at their attitudes to food in school. They found that children’s food choices were primarily ‘unhealthy’ and influenced by media stereotypes, peers (but not teachers), taste and money (with fast food tasting best), and the view that young people are supposed to prefer unhealthy food. Interestingly, it seemed that the more choice they were given, the less likely they were to eat a healthy meal.

Meals supplied within health care settings are another source of dissatisfaction. Poor quality food and lack of menu options on hospital wards are mentioned repeatedly across a number of studies (Healthcare Commission, 2004; Boylan, 2004). Some children have suggested that poor hospital food is an indication that they are not being treated with respect (Boylan, 2004).

An initiative to explore how to support young people in making healthy living choices is reported by Butcher (2005). Four young people took part in a ‘health challenge’ to eat more healthily, and take at least an hour’s physical activity a day, for a week. Their experiences and reflections over this period were recorded and highlighted how the challenge encouraged the young people to think more about healthy living and the things that could make it difficult. Participants also made small but significant changes to their lives, such as taking up running and adopting strategies to help them avoid fast food. It is suggested that more widespread implementation of the ‘health challenge’ could make learning about and choosing health fun, desirable and achievable.

**Obesity and eating disorders**

The National Health Survey 2002 found that over one in five boys (21.8%) and over one in four girls (27.5%) aged 15 or under were either overweight or obese. While there is considerable evidence that attests to the significance of body image for young people (especially females), and demonstrates that young people value looking good and being thin (Chapman et al, 2000; BMA report, 2000; Kings Fund, 2000; Madge and Franklin, 2003; McKinley et al, 2005), there appears to be very little
known about what children and young people think about obesity.\textsuperscript{2} There may, however, be a clue from Holt et al’s (2005) study of 15 young people who attended a residential weight-loss camp. These reported how the positive elements of the camp had been peer and adult support, enjoying themselves, and being given choices of activities. It was suggested that these experiences may normally have been absent in the children’s lives.

Additional evidence comes from ChildLine (McConville, 2003) and young people’s accounts and worries about obesity and how it can restrict their lives. They illustrate how eating disorders do not arise in isolation from other problems, such as relationships within the family, exam pressure, abuse and bullying. Young people often say they fear getting help despite wanting it, and feel they are not fully in control of their own lives.

In response to a public consultation with teenage girls, Tessa Jowell, then Minister for Women, hosted a meeting a few years ago to discuss the use of images of women, and invited young people to participate alongside representatives of modelling agencies, fashion designers, magazine editors, and experts on eating disorders (Morant, 2000). Jowell said, "Young women are tired of feeling second rate because they cannot match the thin ideal that they see so often in the media. For many, poor body image can lead to low levels of self esteem; for some it is far more dangerous, leading to eating disorders and other forms of self abuse." The meeting coincided with the publication of a report from the BMA calling on the media to portray a more realistic range of body images. It suggested that schools should implement media literacy programmes to encourage critical viewing skills, especially in the area of food advertising.

More recently, an Australian consultation study with young people has again emphasised the contradictory messages that children receive about food from advertisers and health promotion exercises, and stressed how these can be a barrier to healthy lifestyles (Hesketh et al, 2005). The authors conclude that promotion of healthy food and activity ‘across settings’ is central to prevention programmes for childhood obesity.

\textsuperscript{2} A consultation exercise is being undertaken with under-11s in Rotherham relating to child obesity issues, which will be completed in 2006.
Physical exercise

‘PE and fitness’ was ranked third in a list of 14 issues considered by school age students in London who completed a questionnaire about health in schools (Hesketh et al, 2005), suggesting that young people do think that physical exercise is important. Nonetheless, many young people suggest that they do not take as much exercise as they should. Nearly two-thirds of those consulted in one study reported that they did not do enough physical activity (Healey, 2002). Moreover, nearly a quarter said that they would like to cycle to school, but only one in fifty actually did so.

When the issue was examined further, several key points emerged. First, it seemed that many young people had mixed feelings about physical education, and did not like the activities they were expected to do. It appeared that physical education would be more attractive to them if they were offered a greater choice of activities. Fear of traffic was a considerable deterrent so far as cycling was concerned.

There are many deterrents to regular exercise. For one of the 120 nine to 18 year-olds consulted in a community survey in North Kirklees (Hooper, 2004) these were: ‘If you are lazy and cannot be bothered; the weather can put you off; when someone comes to your house you get distracted; (I’ld) rather watch sport than play it’.

Alcohol, drugs and volatile substances

In April 2001, the Scottish Executive commissioned Save the Children to ask children and young people about their views on alcohol misuse in Scotland. A consultation with 98 children and young people, in 14 groups, resulted. This demonstrated that young people were very aware of the dangers and health risks associated with drinking, on both a personal and a social level. It also found, however, that a very clear gap existed between knowledge and action, and that most young people said that the pull factors towards drinking were stronger than the push factors away from it. Drinking to get drunk seemed to be the norm, and the reasons appeared complex and multifarious. The influence of friends, advertising, the example of adults, having older brothers and sisters who drink, and a perceived Scottish culture of drinking, were all mentioned. Nonetheless, many young people were making an active and
often informed choice to drink, and the research suggested that younger children have far more definite and negative views about drinking than those found among older young people whose drinking habits have become more established.

Positive reasons for ‘risky drinking’ were identified by in-depth interviews with 64 14 to 17 year-olds who said they get drunk in unsupervised, often outdoor, settings (Coleman and Cater, 2005). Increased confidence in social and sexual situations was the most commonly cited reason, while others were to escape from problems, achieve a ‘buzz’, something to do, the influence of friends, and respect and image. These young people did nonetheless mention negative impacts on their health as well as increased risks to their personal safety. Those most prone to harmful outcomes were the 14 and 15 year-olds who got drunk in unsupervised locations as well as those who reported getting drunk for the 'buzz'.

Interestingly, somewhat the reverse appeared the case from a study that examined drug-taking among young people (Schools Health Education Unit, 2004). It emerged that the older they become, the more likely pupils are to think that drugs are 'always unsafe'. The exception was cannabis, which is considered to be 'always unsafe' by a smaller percentage of the older groups.

There appears to be a considerable variety of motives for using alcohol and drugs. It has already been suggested that young people under stress may be particularly likely to drink alcohol and misuse drugs, and ChildLine (2005) confirmed that callers often reveal a chaotic family life or other serious problems whether they ring to talk about drinking alcohol regularly or over a long period of time, or about a particular experience when they have been drinking. Interestingly, Monaghan and Broad (2003) reported that just under half their sample of young people attached to social inclusion projects used illegal drugs, and a third used them every day. Most said that using drugs had a positive effect on their health and well-being. Many looked after children and young people who took part in focus group discussions (to ascertain the key media for communicating drugs messages) also saw drugs as a normal part of life (Nottingham City DAT).

The reasons for first-time drug-taking were investigated in a national survey on the prevalence of smoking, drinking and drug taking among young people in England in 2003 (Boreham and Blenkinsop, 2005). Although 92% of a national sample of over
10,000 young people (mainly 11 to 15 year-olds) agreed that ‘taking drugs harms your health’, as compared with 10% who agreed that ‘taking drugs is exciting’, almost one in three said they had used drugs at some time. Of these, 64% said they had first taken them because they wanted to see what they were like, 27% to get high and feel good, 21% because friends were doing it, and 13% as they had nothing better to do. This suggests that, among young people in general, taking drugs is not initially a health issue.

The role of volatile substance abuse in young lives is illustrated by an analysis of 356 calls on this subject made by children and young people to ChildLine between 1999 and 2003 (Blake, 2005). A key message is that solvents are not, in the main, used for fun, but are an emotional response to a range of personal and social experiences and problems. It is suggested that volatile substance abuse is a form of self-harm and a coping mechanism to deal with stress. This again highlights the very real barriers to healthy living that can exist in young people’s lives.

**Smoking**

The Schools Health Education Unit (2005) showed how the number of regular smokers more than triples between 12 to 13 years and 14 to 15 years and that, by Year 10, up to 65% will have smoked. Certain factors, such as a close friend or a sister who smokes for females, seem to dramatically increase the risk of smoking, and indeed 56% of the Year 10 females who smoke have a close friend who also smokes. The majority of current smokers nonetheless say they would like to stop.

Monaghan and Broad (2003) also found a high rate of smoking in their sample of young people attached to social inclusion projects. Nearly three-quarters of the 102 young people smoked about 10 to 20 cigarettes every day, and most had started smoking between 10 and 14 years. They were aware of the long-term health risks, but generally felt that the advantages of smoking, such as a reduction in stress and diminished hunger, outweighed the disadvantages.

**Sexual health**

While young people express concern about their sexual health, this does not always influence their behaviour. A study involving 1,500 young people found that they were
concerned about STIs in general but did not necessarily consider themselves to be at risk. They were concerned about pregnancy and STIs, but it was generally the concern to avoid pregnancy that appeared to drive condom use (and the quality of condom use) (Centre for Sexual Health and Brook, 2005). Participants who knew someone who had been diagnosed with an STI often got tested themselves but were not necessarily motivated to use condoms to protect themselves in the future.

An ongoing study by NAZ Project London and the Trust for the Study of Adolescence is investigating the sexual health service and support needs of young people aged 15 to 18 years, from black and minority ethnic backgrounds, and living in Greater London. So far, 3,007 have completed questionnaires and 50 have undertaken in-depth interviews. Findings are not yet available, but the aims of the study are to identify and explore sexual beliefs, attitudes, lifestyles and behaviours among BME youth and develop a sexual health educational resource for practitioners. Young people have been asked about the topics they would like to discuss in school and from whom they feel it would be appropriate to get information from within that setting.
HEALTH SERVICES: THE VIEWS OF CHILDREN AND YOUNG PEOPLE

The next sections examine children and young people’s views of health services in the following areas: information and advice; GP services; school nurses; sexual health services; hospital services; specialist health services; and mental health services. These highlight the common themes that emerge from children’s and young people’s views on their experiences of service use and their ideas for service development. These themes (reflected in the Key Messages at the beginning of this report) include the wish for better information on available services, as well as services that are confidential, welcoming, and open at accessible hours. They also want friendly and ‘respectful’ professionals and other staff who will listen to them and take their views into account.

Information and advice

Young people are often not aware of available health services and how they can be accessed. However they want to be able to find out about these in a confidential way. Most are appreciative of drop-in centres, although these still have room for improvement.

Finding out about health services

A primary concern for many young people seeking information on health services is confidentiality. They may be looking for help for a problem they find embarrassing and they may well not want their families and friends to know.

Several studies provide illustrations. Kurtz and Thornes (2000), for instance, found that secondary school children are often unsure where to turn for help. They want someone they can trust, and are not happy using the school pastoral care system because they do not feel safe talking to teachers on confidential issues. Other studies have suggested that young people want to be able to access information discreetly and unobserved by others, and do not find it sufficient that leaflets and information are placed on open display (Brook, 1998;
Linnell, 2002). A qualitative study, undertaken in a mixed children’s home, discovered that young people particularly want information on mental health issues, keeping fit, substance use and sexual health. However, many are reluctant to request appointments for personal matters and do not feel encouraged to ask about personal health concerns during medical examinations (Bundle, 2002). Young people in another study (Allen, 2003) highlighted their wish for confidential services in relation to substance abuse. Chapman et al (2003) reported how younger children aged 5 to 11 years wanted some information direct from professionals rather than just mediated through their parents. And, in relation to older young people, Sherman-Jones (2003) reported how 16 to 17 year-olds wanted advice on a range of general health topics including diet, sexual health and drugs provided by “professionals who are prepared to listen in a non-judgemental, confidential and accessible setting”.

For some groups of children, there may be additional special considerations. Refugee children, for example, may get confused by language and need special channels for information (Chapman et al, 2003), while children of all ages from Asian families are most likely to seek help and support within the family (Kurtz and Thornes, 2000). Particular issues can face children living in rural areas who may need to have access to transport to get to a town to seek advice (Kurtz and Thornes, 2000). And in a study of looked after children, it was concluded that social workers and carers should not assume that children and young people find it easy to ask about sensitive issues (Dobel-Ober, 2005).

Messages about where to turn for advice may also need to be targeted for particular groups of children. Looked after children and young people who took part in focus group discussions about the appropriate media for communicating messages about the national FRANK drugs campaign, for example, disliked overly-clever creative advertising and the ‘inappropriate’ use of humour. They were more likely to absorb hard-hitting messages. They saw buses, bus stations and other outdoor venues as the most appropriate places for communicating messages, but regarded word of mouth (from a credible source – such as ex-users) as more effective still (Nottingham City DAT). Stockdale and Katz (2002) also suggested that young people show marked differences in accessing and using information, and that ethnicity is an important factor influencing these differences.

It is apparent from studies (eg. Kurtz and Thornes, 2000; Bailey et al, 2001; Allen, 2003; Sherman-Jones, 2003) that many young people do not feel that they know
what is on offer in terms of health and related services. How would they most like to get this information? Madge and Franklin (2003) asked over 2,500 young people where they would most like to turn for help. The number one choice was home (46%), followed by doctors (33%), hospitals (16%), drop in centres (11%), phone (10%), youth clubs (8%), and the internet (8%). There were, however, sex differences. Boys were significantly more likely than girls to say that they would turn to helplines and the internet, while girls were significantly more likely to say that they would seek support from parents, teachers and friends (even though, when asked about sources of help that had been used in the past, 93% had not used a helpline and 84% had not used the internet). These findings were consistent across a range of problem areas (eg. sexual health, drugs, stress, problems at school, and relationships. They also concur with reports from ChildLine, as well as other helping agencies, which point to the great preponderance of girls contacting them on all matters.

To summarise, it appears that a range of methods for providing details about health services for young people is wanted. Nonetheless, and however this information is presented, it should include clear and concise information about the range of services available as well as full details, including opening hours, on how they can be accessed (Bailey et al, 2001).

Drop-in centres

On the whole there seems to be considerable support from young people for confidential drop-in centres, often located at school, where they can gain information and advice on sexual and other matters (eg. Clements et al, 1999; Peckham, 2003; Centre for Sexual Health and Brook, 2005). As one young person commented: 'It would be like a drop-in centre, where they can talk to you, and have tests, with a counsellor there as well' (Sherman-Jones, 2003). A survey of the views of 200 young women aged under 18 revealed that they wanted schools to supply contraceptives, especially condoms, at school, demonstrate their use, and provide information on where else free contraception could be obtained locally.

Young people with experience of drop-in centres do, nonetheless, see room for improvement in the service provided. Based on a 'mystery shopper' report looking at
sexual health services (Health Scrutiny Panel, Nottingham City Council, 2005) described how one major problem identified by young users of drop-ins was the amount of time they were kept waiting. They could get bored or nervous and leave if they had to wait for half an hour or more, and there was a general feeling that extra staff should be on call to come in if there were particularly busy periods. Some young people said they were left alone in a waiting room, with nothing to do, and with no-one checking on them while they waited.

Opening times were another issue for young people. If services are located outside school, they want them to be available during out-of-school hours (Clements et al, 1999; Health Scrutiny Panel, Nottingham City Council, 2005). This applied also to other NHS services such as GP practices (Bailey et al, 2001). They also want sexual health services both in a central location and near to where they lived). It was reported how some young people may not want to travel far to access services whilst others, concerned about confidentiality, may not feel comfortable visiting services close to their homes.

These various messages were reinforced by the findings of a second mystery shopper project conducted as part of the Sheffield Undercover Sexual Health Service Evaluation Scheme. In summary, it emerged that young people wanted more information about the location of services; better experiences in waiting and reception areas; increased privacy; greater efforts to ensure that young people understood the information they were given; and more sensitive treatment by reception staff.

**GP services**

Consistent views on primary care services emerge from the literature. Young people want to be treated with respect; they want services to be welcoming; they want all staff, including reception staff, to be friendly and skilled in communicating with young people; they want to have their privacy respected (concern about confidentiality is a persistent theme, about which young people have very strong views); and they want to be given clear and adequate information. It is evident that young people do not always feel GP services meet these standards of care.
Are young people satisfied with their GPs?

There is some evidence of general satisfaction with GP services. Jacobsen et al (2000), for instance, found that 86% of over 5,000 teenagers who completed questionnaires in 38 schools who said they were satisfied with their most recent consultation. And in another study, commissioned by the NHS Executive in London to provide a snapshot of the issues that children and young people see as important in relation to health and health services, younger children aged 5 to 11 were largely positive about their experience of doctors and community-based healthcare (Chapman et al, 2000). These children particularly valued having toys to keep them amused, and being rewarded with stickers or badges.

At the same time, however, it is clear that children and young people can point to aspects of services they do not like. In Jacobsen et al’s (2000) study, the two most common reasons for dissatisfaction were insufficient information from their GP, and a lack of improvement in the condition that had led to the consultation. Many young people mentioned health concerns they had not sought help for, and it seemed that they were not necessarily turning readily to their GP service for help. Chapman et al (2000) list negative points as the GP’s lack of understanding, fear, injections, and medicines. Refugee children who took part also mentioned confusion and language problems (eg. ‘Sometimes when I go to the doctors I have to say “uh uh uh” cause you don’t know some of the words’).

Levels of dissatisfaction with primary health care appear to increase as children get older, with teenagers becoming particularly concerned about confidentiality and poor communication. In a large study of patients between 14 and 18 years in South Wales, there was ‘an apparent gulf’ between teenagers’ own opinions about health care and the opinions of those providing it (Jacobsen et al, 2001). The teenagers reported a lack of services available from primary care, a lack of respect for teenage concerns, poor communication skills among GPs, and a poor understanding of confidentiality issues. In part this may reflect a conflict between what GPs and young people regard as ‘good’ communication (Richardson et al, 2000). These researchers collected data on teenagers’ views and opinions of primary health care services as well as GPs and found that whereas GPs regarded good communication as the young person listening to the GP and taking advice, teenagers wanted to have more
time with the GP, time to explain their problems in their own way, their health problems explained to them in language they can understand, and made to feel legitimate patients.

Gender may also play a part in young people’s attitudes towards GP services. In a survey of more than 3,000 secondary school students, Madge and Franklin (2003) found that boys were more likely than girls to say that they would seek help from the family doctor for a range of problems. And data from the annual national young people’s survey collated by the Schools Health Education Unit in Exeter indicates that nearly one third (30%) of 12 to 15 year-old girls reported feeling either ‘quite uneasy’ or ‘very uneasy’ on their last visit to the doctor (Schools Health Education Unit, 2005).

Churchill et al (2000) argue that teenagers’ negative perceptions of general practice may have less of an influence on actual consultation behaviour than might be assumed. They compared attitudes towards general practice among 13 to 15 year-old patients, as revealed through a postal questionnaire, with actual consultation behaviour as recorded in case notes. Few significant differences in overall consultation rates were found between teenagers expressing different attitudes about general practice. Differences did exist, however, in perceived difficulty of getting an appointment, feeling able to confide in the GP, and perception of adequate time for the consultation. Fear of embarrassment (eg. for gynaecological problems and contraception) was also associated with lower consultation rates.

As suggested, some young people do not tend to consult family doctors. Walker et al (2002) report on a randomised control trial (RCT) study to evaluate the effectiveness of inviting teenagers to general practice consultations to discuss health behaviour concerns and appropriate follow-up care. The study was carried out with 1,516 14 to 15 year-olds in eight GP practices in Herts, and young people completed questionnaires at the beginning of the study as well as three and 12 months later. The authors report that it was already known that few teenagers receive health promotion advice or information from their GP teams, but that what their study also showed was that teenagers who attend these services welcome GP-based health promotion consultations. Moreover, such consultations provide an effective opportunity to identify and tackle mental and/or physical health problems and
encourage healthy lifestyles. They also reported, however, that the effect of consultations on teenagers’ actual lifestyles is modest.

**The changes young people would like to see**

The literature includes many suggestions from young people on how to make GP services more attractive to children and young people. These include making waiting areas more young people friendly – for example, by providing more appropriate and up to date magazines (eg. on skateboarding or music), playing music, and providing PlayStations (Elliott and Watson, 2000; Chapman et al, 2000; Linnell, 2002; Curtis et al, 2004); having appropriate staff for gender specific problems (Linnell, 2002); displaying information and leaflets in places where young people can access them discreetly without being observed (Linnell, 2002); and extending opening hours to make it easier for young people to visit their GP in the evening, providing dedicated appointment slots for young people, and providing student only services (Bailey et al, 2001; Linnell, 2002).

It is also evident that some young people would welcome better communication skills among GPs, with some children saying that doctors tended automatically to talk to the parent or other carer that accompanied them (Elliott and Watson, 2000; Elliott et al, 1996). The importance of friendly and discreet receptionist services to young people has also been emphasised (Linnell, 2002).

**Confidentiality**

The worry that GPs may not preserve the confidentiality of young patients is a persistent theme across studies (Burack, 2000; Linnell, 2002; Percy-Smith et al, 2003). Reception staff can be a particular cause for concern, and young people complain that reception staff should not mention the reason for their visit when anyone else is in earshot (Linnell, 2002; Sherman-Jones, 2003). Many young people appear to be particularly wary of approaching their GP for sexual health services for this reason (Smith, 2001; Burack, 2000), and the evidence suggests that practices need to change if young people are to be convinced that GPs are a reliable and trustworthy source of help and support.
Confidentiality can be a particular issue for young people living in rural areas (Kurtz and Thornes, 2000; NCB, 2001). Kurtz and Thornes report on an interesting project in a rural secondary school in the South-West which provides a primary care service for pupils on school premises. This has apparently removed some anxiety about lack of anonymity in the rural location, and the service is reported to be well received and well used.

**Looked after young people**

There is good evidence that looked after children have a range of unmet needs in relation to both physical and emotional health (eg. Brown et al, 2005; DfES, 2005; Residential Care Health Project, 2004). They may also face particular difficulties in using GP services. Bundle’s (2002) qualitative study undertaken in a mixed children’s home found that many young people were reluctant to ask for appointments for personal matters, and did not feel encouraged to ask about personal health concerns during routine medical examinations. Some looked after young people, consulted by the National Children’s Bureau during the development of the National Healthy Care Standard, felt that children in family units were given more support in accessing health services. They thought that health professionals were more likely to listen to parents, and also that the majority of their own health and wellbeing needs could be met through the vigilance of their carer and social worker and the consistent, confidential support of an interested doctor or nurse (Chambers, 2002). Having to change doctors regularly was a particular concern for looked after young people. In another study, nearly a quarter of younger looked after children (aged 11-14) were unsure who their doctor was (Dobel-Ober, 2005).

**Children with special health needs**

Not surprisingly, children and young people with special health needs may have a rather different perspective on GP services from their peers. Chapman et al (2000) found that disabled children aged between 5 and 11 years had a ‘more intense’ experience of community-based services than others, and were particularly concerned about missing school and their friends. They also preferred services that were provided at home or at school than at the GP surgery.
Children who use specialist health services may become frustrated at the lack of expertise or understanding of their condition among more generalist health practitioners. Those with type 1 diabetes and their parents have, for example, been shown to be critical of the ‘severe’ lack of knowledge of non-specialist health practitioners which they felt compromised appropriate levels of care (Sutcliffe et al, 2004).

**Understanding what’s on offer**

Some studies point towards a certain amount of confusion among young people about the services available to them from their GPs. A questionnaire survey of more than one thousand 13 to 15 year olds found that two thirds (66%) of respondents were aware of sexual health services offered by GPs, and three quarters were confident of being given helpful advice (Burack, 2000). However, more than half (54%) thought they had to be over 16 to access sexual health services via their GP. In a research study on the acceptability and accessibility of mental health services to young people from black and minority ethnic backgrounds, it emerged that many young people thought that GPs dealt only with physical health problems (Street et al, 2005).

Young people may not always understand how their GP’s service operates out of hours. A questionnaire study in Dorset, to find out how much young people aged 16 to 25 years understood about services available over the Christmas and New Year period, found that although most knew about A&E services, emergency pharmacy and ambulance services, they were unclear about GP services (Bailey et al, 2001). These young people said they would welcome student only services, or extended opening hours for practices with large numbers of students.

**The role of schools and other settings**

Health provision occurs in many settings other than traditional health services. Schools, for instance, are important in monitoring children’s health on a daily basis as well as providing more specialist support where children have special needs of some
kind. Studies of young people with medical needs tend to confirm the findings that relate to health services more generally. Young people indicate that they like teachers who ‘understand’ them (Lightfoot et al, 1999) and treat them as ‘normal’ (Cavet, 2000). A recent study of six and a half thousand second school pupils (Datta et al, unpublished) found that, among other things, young people wanted improved facilities and services, including a better medical room, improved physical access, and special facilities and activities for students with disabilities, special educational needs and medical needs. Responses were fairly similar for pupils who reported a long-term medical condition and the sample as a whole. Those with medical needs were, however more likely to regard their school as good at supporting students with health needs and not in need of improvements. They were also slightly more likely to suggest there should be information and training available on medical conditions and that schools should provide health education and health checks. The findings also indicated that those in schools with a full-time member of staff to support students with medical needs were more likely to feel that needs were being met.

Juveniles in custody raise other issues. Based on information provided by young people held in custodial institutions during 2001 to 2003, Challen and Walton (2004) reported that about a quarter of the sample of 1,222 (representing 44% of the juvenile prison population) reported insulting remarks from staff and over a third said they had felt unsafe at some point during their time in custody. Boys rated the healthcare in their establishments more highly than did girls, although access to showers was poor for boys and varied across institutions for girls. A quarter of all young people said they had not received a visit from a friend or family member.

These examples suggest that the same kinds of things contribute to the health and well-being of most young people, whatever their characteristics and circumstances. Nonetheless, those in particular settings may be less likely than others to gain or achieve what they need, or they may have special requirements in those settings. This reinforces the message that young people usually know best about their own personal wants and needs, and that the best way of finding out what these are is to ask them.
Measuring height and weight

The government’s strategy to prevent obesity, as outlined in the Public Health White Paper *Choosing Health*, includes proposals to measure children’s height and weight at primary school. This is both to monitor levels of overweight and obesity at a local level, and to identify individual children who might be in need of support and intervention.

Several investigators have reported on activities to gather relevant information for these tasks. Routh et al (undated), for instance, collected information on height and weight via a numeracy and data-gathering lesson from 252 nine to 10 year-olds in Birmingham to provide a model for examining the prevalence of childhood obesity at a local level. The views of children were not reported, and the data collected were anonymous, but it seemed that collecting this information was not problematic. In a separate exercise to establish the prevalence of obesity in Leeds, Rudolph et al (undated) weighed and measured 999 children from the reception class and Years 4 and 8 in primary and secondary schools. Again, neither the views of children nor problems were reported.

Some initiatives have sought to find out what children think about being weighed and measured at school. Recent consultations by the National Children’s Bureau (2005) asked 219 primary school children between 4 and 11 years, from three schools in different parts of the country, for their views on where measuring should take place, who should do it, how the results might be used, how parents/carers might be involved, and how the intervention could provide opportunities for them to learn about health and healthy lifestyles.

The findings demonstrated: first, how children’s understanding of the concept of being weighed and measured increased steadily with age; second, that most thought monitoring their size was important for providing information to help them improve their health; third, that they had some anxieties about the procedure and would usually like their parents/carers to be with them when they were weighed and measured; and fourth, that they wanted to be kept properly informed about what was happening and their own results.

Similar messages emerged from another consultation with ten children aged between 6 and 10 years (six girls and four boys) who had either disabilities or complex health
needs (Triangle, 2005). These children also seemed to feel that being weighed and measured could be helpful in promoting health, especially if they were overweight and needed to go on a diet. However, their conditions meant that individual needs (e.g. physical mobility) should be taken into account: some of these children specified that they wanted to be able to choose whether or not to take part. Privacy and confidentiality were key issues for these children who acknowledged the embarrassment that overweight children might feel. On the whole they did not like the idea of being weighed and measured at school, particularly if friends were around, and most said they would prefer it to be done at home or at the doctor's surgery.

A briefing paper from Eastern Hull PCT (undated) on preventing, identifying and managing overweight and obesity among children and young people in Hull and the East Riding outlined how a local initiative is developing a strategy for identifying the early signs of obesity. Still at an early stage, the purpose of the first tranche of the project is to provide recommendations based on current evidence for best practice in the screening of overweight and obesity in children and young people up to the age of 11. After this, the next step will be to work with children and young people, as well as parents, carers, the food industry, schools, and sports and health workers, to ensure the availability of a range of evidence-based preventative measures, interventions and treatments.

**School nurses**

There is limited evidence on young people’s views of services offered by school nurses, but the evidence there is suggests a fairly high level of satisfaction from those who have had contact with a school nurse. More generally, however, young people do not readily identify the school nurse as a potentially significant source of help and support for many problems. Girls are more likely than boys to use her services – most commonly for minor illnesses and sexual health matters.

Few studies offer direct evidence of children’s views of services provided by school nurses. A literature review by Watters (1998) reported an emerging consensus on the role of the school nurse, but children’s views were not an explicit part of that consensus. DeBell and Everett (1997) noted that “what is missing in virtually all research about the role and function of school nurse is the need to consult children and young people themselves on all issues concerned”.

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One study that does examine young people’s views of school nurse services in some
detail surveyed more than 3,000 young people at six secondary schools (Madge and
Franklin, 2003). Questionnaires were used to investigate young people’s views on
their school nurse services, and their attitudes towards various potential sources of
help and support (eg. family, friends, teachers, helplines, school nurses), for a
diverse range of possible problems. The study found high satisfaction rates with the
school nurse. Of the 889 pupils who reported contact, more than three quarters
(77%) said the school nurse had been helpful (51% ‘quite helpful’, 26% ‘very
helpful’), and only 12% said the nurse had not been helpful.

School nurses were not, however, commonly identified by the young people as a
preferred source of support for problems. Pupils were asked who they might turn to
for help or information in relation to stress, sexual health, drugs, smoking, diet and
weight, personal appearance, problems at school, minor illnesses, and relationships
with friends or parents, and it was apparent that families and friends were seen as
most important in this role. Where the school nurse was mentioned, this was most
likely to be for concerns about sexual health or minor illnesses. It is possible,
nonetheless, that this low rate of acknowledgement reflected the limited school nurse
resources in schools. Only one school had a school nurse permanently on site and,
not surprisingly, young people at that school were more likely to turn to her for help or
support than at any of the others. Indeed, at the other schools, there was
considerable variation in pupils’ knowledge about how to contact the school nurse.

A small number of school nurses, interviewed as part of a study comparing the views
of young people and professionals, said they thought young people found it difficult to
see them as a confidential service because they were seen talking to teachers in
corridors (Sherman-Jones 2003).

Sexual health services

Confidentiality is a major and well-established concern for young people using, or
contemplating using, sexual health services. Young people want services to be
confidential, welcoming, and discreet; and they want staff to be friendly, non-
judgemental, and not prone to lecturing. Drop-in services are generally strongly
preferred. For young people, opening times are also an important aspect of accessibility. They want services that are open when they can most easily use them (ie. at weekends, after school, and in the evenings). Young gay men and lesbians want services that understand their sexual orientation, and want to encounter staff that do not make assumptions about heterosexuality. And for young people living in rural areas or smaller communities, anonymity may be an even more pressing concern than confidentiality.

**Views and experiences**

Young people’s anxieties about confidentiality, judgemental staff attitudes, and embarrassment about being seen or appearing stupid, were made apparent by research carried out for Brook that involved focus groups of young people aged between 13 and 18 years (Brook, 1998). Ease of access and security against homophobic attacks were also important. The factors that were most likely to deter young people from using the service were being embarrassed at reception or being ‘lectured’ about behaviour by staff. Older boys also said they did not like being pressured to discuss private matters.

Those who took part in the study said they obtained sex advice from both formal and informal sources, which changed as they matured and became more confident. However, preferences differed according to sexual orientation. Heterosexual young people tended to rely on friends as a main source of advice, whereas young gays and lesbians relied on confidential helplines and specialist services.

Young people living in rural areas may have additional problems or anxieties about accessing sexual health services (Donnelly, 2000). Garside et al (2002) found that a particular concern for youngsters in small communities is the difficulty of remaining anonymous. Visibility and lack of privacy can be a more pressing concern even than the more usually reported need for confidential consultations. Those taking part in focus group discussions reported the fear of being seen attending a health service and their visit being reported to their parents through concern or gossip. For girls, the sense of being under scrutiny in their community was particularly acute.
Sexual health services need also to be sensitive to the needs and views of particular
services by previously looked after young people are influenced by their experiences
of being ‘let down’ early in life, and the lack of trust this creates. A small-scale study
in Bristol involving 34 young women, aged 16 to 20 years, from different socio-
economic backgrounds found that young women from more socially advantaged
backgrounds were more likely to use emergency contraception (Jewell, 2000).

The ideal service

A Brook study to determine what 13 to 18 year olds want from a sexual health
service report that young people described their ideal service as having the following
characteristics (Brook, 1998):

- confidential
- easily accessible with minimal fear and embarrassment
- located on a side street, near the town centre in a non-homophobic
  area
- clean, smart premises discreetly signposted with frequent opening
times
- a walk-in service (no appointment necessary)
- reception and waiting areas designed to minimise embarrassment
- staff who are friendly, respectful, non-judgemental, and use clear non-
  medical language
- staff who are informed on gay and lesbian issues and do not make
  assumptions about heterosexuality

These characteristics are largely typical of young people’s views recorded elsewhere
in the literature (Hudson and West, 1996; Clements et al, 1999; Smith, 2001;
Donnelly, 2000; Nwokolo et al, 2002; Chambers et al, 2002; Ingram et al,
unpublished). Smith, for example, asked 117 young people, aged under 25, in a
small town in England to define their ideal sexual health service. They described a
holistic youth service based in an accessible non-clinic setting which would also offer
advice on other health issues such as smoking, drugs, alcohol and acne, as well as
social issues such as housing and benefits. The young people were reluctant to turn to their GPs for sexual health services. Only 15% were prepared to do so (for under 16s, this fell to 4%), as compared with 94% who were happy to use either the Family Planning Clinic or local young people’s clinic (Smith, 2001).

**Confidentiality**

Confidentiality has long been established as the over-riding concern for young people using sexual health services. In October 2005, Brook launched a campaign – Wise Up! – in response to concerns that young people’s rights to confidentiality were under threat. In a survey of more than 700 young people under the age of 25, 53% of all respondents – and 62% of those under age 16 – identified confidentiality as the single most important issue to them in seeking advice about their sexual health (Brook, 2005). Two thirds said they would be less likely to seek advice if they knew health workers could pass information about underage sexual activity on to social workers. Almost three quarters (74%) of those under 16 said they would be less likely to use services in such circumstances.

When asked if health professionals should be able to tell anyone else about visits from under 16s, more than nine out of ten under 16s – and almost four in five of all respondents – said no. Asked whether there were any situations in which it might be acceptable for a health professional to breach confidentiality, four in ten still said no. Just over a third said it would be acceptable in some circumstances, such as abuse, rape, or where a young person was at risk of serious harm, and just under a quarter did not know or did not answer the question.

Earlier research with groups of 15 and 16 year-old girls found that the girls’ concern about confidentiality focused on informal or inadvertent breaches, ‘nosey’ or ‘gossipy’ receptionists, and confidential information being sent in the post and intercepted by parents (Brook, 1999). The young women were also anxious whether disclosure of pregnancy by an under 16 year-old would remain confidential, and whether referrals for abortion would be made in confidence. Burack (2000) found that 58% of over a thousand 13 to 15 year-olds who completed questionnaires at school expressed

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3 The Wise Up! campaign was launched on 19 October in response to consultation on proposed government guidelines which could lead to professionals who work with young people being required to report all sexual activity among younger teenagers to social workers and the police.
concern about whether their confidentiality would be preserved if they were to access sexual health services through their GP.

**Knowing where to go**

There appears to be considerable confusion about sexual health services. There is evidence that young people do not always know where they are (Smith, 2001) or how to access them, or exactly what they have to offer (Clements et al, 1999; Burack, 2000). Clements et al found that young people in Hampshire, for example, had poor knowledge of the specific provision provided locally by GPs, family planning clinics, and youth family planning clinics.

There is, in particular, evidence of confusion and wariness in relation to services available from GPs. As already reported, Burack (2000) found that just over two-thirds of the over one thousand 13-15 year olds in the study were aware that GPs provide sexual health services, but more than half thought they had to be over 16 to access them. Smith (2001) found that fewer than one in twenty under-16s was prepared to visit their GP for sexual health services, and that even for older young people the proportion was still less than one in six. Churchill et al (2000) found that fear of embarrassment was associated with lower GP consultation rates for contraception among 13 to 15 year-olds.

With the help of young people, Brook (1996) developed guidelines on promoting young people’s sexual health services. The methods of promotion most favoured by the young people were posters, leaflets, and flyers, displayed in places where they could be accessed discreetly. Materials need to be attention catching and stylish, emphasising words such as ‘sex’, ‘confidential’, ‘advice’ and ‘free’ but avoiding words such as ‘clinic’, ‘family planning’ and ‘problems’. The young people thought promotional visits to schools and youth centres were helpful, as were adverts in local papers and on local radio. A separate survey of more than 800 young people in Hampshire (comprising 696 school pupils and 108 clinic attendees) found that advertising clinics in schools was felt to be the best method of publicising sexual health services (Clements et al, 1999).
Sex education

Although experiences are mixed, there is evidence of widespread dissatisfaction with both the quality and amount of sex education that young people receive at school (Hudson and West, 1996; Jewell, 2000; YWCA, 2001). Almost 400 young women under 18 who completed questionnaires in one study wanted sex education to provide more detail about contraception and STIs, and to place more emphasis on feelings and relationships (YWCA, 2001). They thought sex education should start at an earlier age and be given more priority (ie. more lessons) in the school curriculum. Young women also argued for boys and girls to receive sex education separately, and for time to be made available for one-to-one confidential question and answer sessions.

Hospital services

Children and young people attending hospital want to be involved in decisions about their care, they want to have their privacy respected, and they want to be given good information that they can understand easily. If they have to stay in hospital, then they want to do so on wards alongside other young people of a similar age; they want hospital staff to be kind, friendly, and sympathetic; they want to be cared for in a pleasant and attractive environment, with enough interesting activities to keep them occupied; they want enough staff to care for them effectively; they want their pain to be managed effectively; they want to have a choice of decent food; and they want to be discharged promptly and efficiently.

Children as individuals

Children and young people emphasise that they want to be treated as individuals. This means not only that they want to be listened to and treated with respect, but that they want it to be recognised that there will be children and young people who sometimes dissent from a majority view. So while a consistent theme across the literature is that children and young people want to be given more information and

4 The UK Youth Parliament identified sex education as its national health campaign priority for 2005. The aim is to improve and standardise sex education across the UK. See www.ukyouthparliament.org.uk
involved in decisions about their care, one study identified by the Children’s Voices Project found that a small number of children mentioned that they ‘preferred not to know everything’ (Boylan, 2004). Also, although children and young people usually want to be treated alongside their peers, some children who are very ill may prefer to be separated from those who are less ill (McArthur, 2004).

Not surprisingly, the evidence suggests that younger children and their older counterparts can have rather different priorities (McArthur, 2004). Effective management of pain relief is important to all children and young people, and both younger children and teenagers want to be given more and better information (McArthur, 2004; Boylan, 2004). However, when children aged 7 to 11 years were compared with those aged 12 or over within a consultation study of more than 350 young people, somewhat different concerns arose. For those aged 7 to 11, the priorities were: help me when I’m hurting; explain treatment so I understand; make sure people looking after me agree what they should tell me; use magic cream before injections; provide a place off the ward to see family and friends; and let me see outside and get fresh air. In comparison, the priorities for those aged 12 or over were: dedicated adolescent wards; less time waiting at clinics; more fully qualified doctors and nurses (rather than junior doctors); more activities on the ward; pain relief when I need it; and let me know what you are saying or writing about me. Boylan (2004) has further indicated that older young people are more likely to emphasise the need for privacy.

**The hospital environment**
The Children's Voices Project\(^5\) uncovered a wealth of comments and suggestions from children and young people on how their experience of being in hospital could be improved. There were calls for phones on the wards, as well as access to computers so that young patients can e-mail family and friends; and calls for private showers. Games and toys were popular, but some young patients felt that not enough are provided, that they are not always age appropriate, and that they may not be available when children and young people want to use them (e.g. in the evenings). Responses on catering were mixed, but it is clear that there is widespread dissatisfaction among young patients about the quality of food on offer and the limited choices available to them. Suggestions for better communication included being introduced to everyone on arrival at hospital. There were also many complaints about the noisiness of wards which can make it difficult for children to sleep.

A report on three workshops attended by four girls aged between 13 and 16 years (Wray and Brook, date?) identified some additional concerns for hospital services. In terms of inpatient factors, they mentioned the importance of keeping people healthy in hospital and making sure they do not get infections, keeping patients occupied, providing a special room for teenagers – designed by teenagers - that had television, computer, CD player and other equipment, and separate cubicles for teenagers to ensure their privacy. They also pointed to the need for plenty of staff, including doctors, to be present on the ward, and for consistency in the carers looking after them. In relation to out-patient services, consistency in the doctors they saw at appointments, minimising the number of necessary clinic appointments, reducing waiting times, providing clinics during school holidays and possibly at weekends, and synchronising different clinics so they could be attended at the same time, were all mentioned.

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\(^5\) The Children’s Voices Project (Boylan, 2004) is an important ongoing source of information about the views of children and young people using healthcare services. The project was originally established in 2003 at the request of Commission for Health Improvement (CHI) commissioners as a means of ensuring that children’s voices influence future inspections. CHI contacted relevant statutory organisations, as well as 104 voluntary organisations working solely with children and health issues. Altogether, 116 reports were received, of which 59 included direct feedback from children and young people. All relevant feedback from children and young people have been extracted from the reports and entered onto a searchable database containing more than 750 individual pieces of feedback, as well as details of all 116 reports. The project is now being taken forward by Commission for Healthcare Audit and Inspection (CHAI) - the Healthcare Commission.
There is evidence that adolescents are overwhelmingly in favour of dedicated adolescent services in hospital (Oppong-Odiseng and Heycock, 1997; Viner and Keane, 1998). They want to be with other young people, but they do not want to be on children’s wards.

**Improving the service**

The Healthcare Commission’s Young Patients Survey (2004), a large-scale and innovative initiative, showed a tendency for young people to rate hospital-based healthcare highly. The views were gathered from more than 62,000 young people and/or their parents about the children’s recent experiences of inpatient or day service care, and more than 90 per cent rated their care as ‘excellent’, ‘very good’, or ‘good’. Moreover, more than 90 per cent of those seen in A&E thought their care had been either ‘very organised’ or ‘fairly organised’. Only 7% thought it had been ‘not at all organised’.

This overall picture, however, masks underlying concerns for young people. First, nearly half the young patients said they wanted to be more involved in decisions about their own care: in practice, parents were more likely to be involved in decisions about care than the young patients themselves, and were generally provided with more information. Many young patients complained of staff talking in front of them as though they were not there, and nearly two thirds said there had not been enough nurses to care for them properly. Other concerns included hospital food (nearly half the young patients rated the food provided as only ‘fair’ or ‘poor’), discharge delays (over one in six were delayed for more than four hours), and admission delays from A&E (more than half had to wait at least two hours, with a quarter waiting four hours or more).

Although information provided at discharge on what to expect, danger signals, and medication, was rated highly by the respondents, the study authors concluded that there is still scope to improve explanations about procedures and risks, benefits and expected outcomes.
Specialist health services

Evidence from children and young people who use specialist health services has shown that many of their views reflect those of their peers who do not have specialist needs: in other words, they want to be involved in decisions about their care and treatment; they want to be treated with respect; and they want to be given clear and adequate information. When attending as outpatients, they dislike waiting and want more entertainment and things to do in the waiting room. During spells in hospital, they want to be treated alongside other young people of a similar age; they want to be cared for in a pleasant environment; they want staff to be kind, friendly and sympathetic; and they want to be given a choice of decent food.

These children and young people will have had a more intense experience of services than most of their peers, and so have rather a different perspective on health services. They are generally particularly appreciative of the skills and expertise of the specialist health practitioners whom they see regularly (Datta, 2003), but may be frustrated by shortcomings in the knowledge of non-specialist health practitioners (Sutcliffe et al, 2004). Many children and young people with a chronic or enduring illness are likely to see themselves as experts in their condition. If non-specialists do not recognise young people’s expertise, children may lose confidence in practitioners’ ability to care for them effectively (Sutcliffe et al, 2004).

Experiences of specialist services

Particularly important to young people with specialist health needs is getting the best possible treatment and care for their condition. For this reason, children and young people with cancer, who participated in a consultation event to assist in the development of a NICE guideline, expressed a preference for being treated at a regional centre rather than a local hospital, even though this often involved a long journey from home (Datta et al, 2004). They thought that the treatment they received at a regional centre was superior, staff had more knowledge about cancer treatments, and knew the children better. When being treated in local hospitals, children said they felt that they and their family often had more knowledge about their condition than the staff. Some complained that staff in shared care hospitals were ill-
informed about their treatment, and that they had to explain their needs again and again (Datta et al, 2004).

Discharge is another concern for children and young people with special health needs, with some reporting that they have had to spend far longer in hospital than justified by medical need (Noyes, 1999; Boylan, 2004). They can feel deprived of their education (Clarke et al, 2005) and may prefer other forms of care. A qualitative study comparing 40 families’ experience of hospital and home care found that seven out of eleven children, and nine out of ten parents, stated a clear preference for ‘hospital at home’ care (Sartain et al, 2001). This picture was confirmed by a small-scale in-depth study of 18 young people who were ventilator dependent. It found that the young people expressed frustration at their treatment by professionals (Noyes, 1999). First, not all young people had their care packages reviewed regularly: these care packages, which were to enable young people to live at home, varied widely and were not based on individual need. Second, interviewees felt that little work had been done to prepare them for transfer to adult services. And third, they said they had spent periods in hospital even though there was no longer any medical need for them to be there.

Clarke et al (2005) found, on the one hand, that young people with cancer and their parents were generally satisfied with the support they received from nurses and social workers in hospital, the preparation for treatments, and the medical information they received about the illness. On the other hand, however, there was a lack of standard practices and procedures across treatment centres and in the provision of support for transition to adult care. There were also gaps in the availability of counselling staff, teenage facilities and activities, and age appropriate information in different languages.

**The transition of care from paediatric to adult services**

The transition from paediatric to adult care has already been mentioned as an important issue for children and young people. This is relevant to all forms of health care, but perhaps particularly significant for young people with special health needs who may have built up relationships with professionals who have become well acquainted with their particular condition and circumstances.
Datta (2003) interviewed 85 young people with diabetes, aged between 10 and 20 years, and showed how they may have mixed feelings about this change. While young people often welcome feeling more grown up, they can at the same time be worried about losing contact with staff they know and like. Although this research study aimed to identify optimal models at transition, it emerged that the people involved were as important as the specific arrangements. Nonetheless, good preparation for, and information about, transition was welcomed by young people.

More hypothetically, Wray and Brook (date?) explored the move from paediatric to adult care with four girls who were attending services in paediatric settings and had not yet had experience of transitions. Prospectively, however, they identified the importance to young people of good information about what would happen, and a gradual integration into adult services. They wanted staff used to working with teenagers and whom they could easily identify with, and they welcomed the idea of being introduced to the new unit prior to their first visit.

**Communication**

How children are given information, and the manner in which they are consulted, is important to them. Those consulted in relation to the NICE guideline felt that sometimes doctors offered choices to their parents when they could have made a decision themselves. Many felt that staff sometimes talked as though children were invisible, addressing their comments exclusively to parents. Children were also unhappy when nurses talked about them and their illness in front of others on the ward (Datta et al, 2004). Similar comments were made by children suffering from diabetes in a separate consultation (Datta and Olle, 2002). ‘Nurses talk to your parents instead of you, but your parents don’t have diabetes’ reported one young person.

The 8 to 14 year-olds taking part in the consultation about cancer were asked to design the best environment for learning about their diagnosis. The rooms designed by the children were broadly similar: colourful with sofas or comfortable chairs, pictures and toys. Children did not want to be told in a clinical, impersonal place. Many stressed that they wanted to be told in a private room with only their parents
and the consultant present. One child thought there should be a room specifically designated for the purpose of giving a diagnosis; another said he would have preferred to be told in his own bedroom at home. Some said the diagnosis should have been explained more sensitively with more time allowed for questions and answers. (One young person had learnt of the diagnosis in a telephone call!)

Although a few of the younger children (aged 5 to 7 years) consulted as part of the same exercise said they liked to know what was going on and what all the medical apparatus was for, most preferred to discuss their illness in a less explicit way. Younger children particularly valued reward systems, such as letting children play with toys or sweets after injections or operations (Datta et al, 2004). However, younger children also wanted rooms to be colourful, with lots of toys and art materials to play with. Some said they wanted to be able to play outside. They thought friends should be able to visit more often, and that they should have access to mobile phones to call home. Younger children particularly valued ‘funny’ and ‘happy’ doctors and nurses who made them laugh. Although some disliked the food on offer while they were in hospital, they tended to complain about it less than older children and young people.

**Young people as partners in their health care**

Sutcliffe et al (2004) set out to establish whether young children can take an active part in managing their own diabetes care, and work as partners with health practitioners. They interviewed 24 children (aged 3 to 12) with type 1 diabetes, and 29 parents. Children and parents reported high levels of knowledge and skill and high levels of satisfaction with the care they received from specialist diabetes staff. However, interviewees were critical of the ‘severe’ lack of knowledge of non-specialist health practitioners, who were said to be unable to provide adequate and safe care. The authors conclude that practitioners need to be able to recognise and learn from the knowledge of children and their parents, and work with them as partners to provide effective care and support.

There is also evidence that children can identify their own information needs before admission for elective surgery (Smith and Callery, 2005). Nine children aged 7 to 11 years were interviewed using the ‘write and draw’ technique. Between them, the
children identified 61 questions about their forthcoming admissions. These included questions about procedures, anaesthesia, timing, hospital environment, pain and feelings, family support, as well as about their own condition. The authors concluded that children can identify their own information needs and so contribute to the development of pre-admission education.
Mental health services

In many respects, the key themes that emerge from the literature relating to children and young people’s views on mental health services are not dissimilar to the views expressed about health services more generally. Children and young people who use mental health services want to be listened to; they want to be seen as individuals; they want to be consulted about their treatment and to be offered choices (consent is a major issue for young people using mental health services); they want to know that their confidentiality will be maintained; they want to be given clear and adequate information; they want to use services that have been designed for people of their own age; and they want staff to be friendly, approachable, sympathetic and able easily to engage with young people. Young people using inpatient mental health services want to be more involved in their treatment and care, to be given more information about all aspects of their care, and to be involved in discharge planning.

But there are wider issues also. For young people using mental health services, lack of adequate information appears to be an even greater problem than it is for young people using other healthcare services (Svanberg and Street, 2003; Street et al, 2005). Mental health services are poorly understood. Many young people do not know where to turn for help, or what form that help is likely to take. Young people’s understanding of the role of different mental health practitioners and services appears often to be sketchy or non-existent, and services seem poor at explaining these roles.

What young people want from services

Based on a review of the literature, Street (2004) has described what children and young people who use mental health services want from them:

- information to be shared with them
- to be listened to
- to be given information about treatment, both prior to accessing services and on entry
- staff who are approachable, available, and skilled in engaging young people
• staff who are empathetic, trustworthy and able to make things happen
• time to get to know staff and establish a relationship
• to be able to give their consent to treatment, have their confidentiality maintained, and their need for privacy respected
• services to be accessible and age appropriate – this includes location, timing and flexibility of appointments, and the ambience of facilities
• in-patient facilities to provide interesting activities, education provision, and support on discharge, as well as being clean and providing good food.

In an ongoing research study for NCH, Allard has been exploring young people’s experiences of mental health services and whether the services meet their needs. Young people taking part in the study were very clear about the support they valued: they wanted the service to come to them, and they wanted it to be informal, non-stigmatising, and available when they needed it.

Allard has identified a number of key areas in which the traditional configuration of mental health services clashes with what young people say they need. For example:

• young people are often reluctant to seek help except when in crisis, yet services operate an appointment system which may take weeks or months
• young people are reluctant to admit to symptoms of poor mental health, even to trusted workers, yet the system often requires a GP referral to services
• the chaotic lifestyle of some young people or feelings of depression may sap their motivation, yet the system de-refers anyone who misses an appointment
• for young people, there is an inverse relationship between geographical distance and motivation to attend, yet services are rarely community based

Certainly there is evidence that giving young people a say in designing mental health services does bring benefits (Kirsch, 2005). The children’s mental health charity, Young Minds, has produced a guide for practitioners describing different models and benefits of children’s participation, and a checklist for staff to consider when developing user participation in their services (Street and Herts, 2005). A qualitative study designed to explore 10 and 11 year olds’ understanding of the concept of mental health, found that they had a sophisticated understanding of mental health issues. The authors conclude that the children’s levels of interest and understanding
would qualify them for a place in discussions about services for their age group (Roose and John, 2003).

**Information and knowing where to turn**

While information is a key issue for all children and young people using healthcare services, it appears to be a particular problem in relation to mental health services. Ahmad et al (2003) report that once children and young people in their study had made contact with services, their experiences were positive. However, knowledge and understanding among most young people about what mental health services are, what they have to offer, and what different mental health professionals do, is limited (Svanberg and Street, 2003; Street et al, 2005). Kurtz and Thornes (2000) report that secondary school children point to a lack of accessible, sympathetic and trustworthy sources of advice and help over stress-related, relationship and emotional health concerns.

Many young people who have used inpatient services report how their limited knowledge of available mental health services contributed to the way their situation deteriorated to crisis point before they were able to receive any help (Svanberg and Street, 2003). Knowing where to turn may be a particular problem for some young people from black and ethnic minority groups. For example, Yazdani (1998) report that young Asian women in Newham often had little awareness of mental health support services, and their ability to seek help was sometimes limited by themselves, their families and the community.

**Black and minority ethnic children and young people**

A national study (Street et al, 2005) collected the views of young people from black and minority ethnic groups about their awareness, understanding, and experiences of mental health services. The data were gathered from in-depth interviews with 76 young people, aged between 16 and 18, who included those who had direct experience of using mental health services as well as those who did not.
The study highlighted many concerns common to young people in general, such as worry about the stigma associated with using mental health services and fears about confidentiality not being preserved. Young people who had been in touch with services complained about long waiting times for an appointment, services that were open only at inconvenient times, services that were difficult to get to, and a sense of being passed around (without explanation) and having to re-tell their story to several different professionals.

Young people who took part in the study had very limited understanding of mental health services and most, even when they thought they needed help, did not know how to access it. Some young people thought GPs would be able to help only with physical health problems. Many young people from black and minority ethnic groups also expressed concerns about going ‘outside the family’ for help and felt that the influence of parents’ perceptions of services are not widely understood. Young people living in close-knit communities were particularly anxious about anyone finding out that they had used services. They thought that schools, colleges and local youth and sports clubs should be used to disseminate information about mental health services to large numbers of young people.

The lack of interpreting services can be a problem for some young people from black and minority ethnic groups, as can the lack of choice in the gender and cultural background of key members of staff. Young refugees and those seeking asylum found it difficult to access help and support from services to deal with past traumatic experiences, loss, and grief. Many said that having to travel to distant services compounded their difficulties because of problems negotiating an unfamiliar public transport system.

Suggestions for how services could be improved included more flexible opening hours that reflect when young people can attend (ie. in the early evenings and at weekends), more interpreters, and a greater understanding on the part of professionals of the cultural context of issues that impact on young people from black and minority ethnic groups, including those with refugee status or who are seeking asylum. On the other hand, however, some young people stated that they did not have any particular religious or cultural needs, and they did not want staff to make assumptions about them. A few young people suggested that a befriending scheme would be useful for young people who are fearful of approaching services.
Inpatient services

Young people consulted during a two-year study on inpatient mental health services said they had found some aspects of their care helpful and others unhelpful (Svanberg and Street, 2003). Over half wanted to have a degree of choice over the treatment programmes they participated in. Another key concern was knowing when they were likely to be discharged. It was unsettling not to know, and they wanted to be involved as early as possible in their discharge planning. Time to establish relationships with staff and build up trust was also valued. They wanted to talk and to be understood, and saw informal chats about everyday things as essential in building relationships. Some young people spoke about needing to feel that it was not ‘just a job’ for staff (Svanberg and Street, 2003). Other issues for young people using mental health inpatient services included boredom, a lack of privacy, and a shortage of information – about rules, the structure of the day, how long the initial assessment would last, and the roles of staff, as well as their own mental health problems and prognosis.

Counselling

Counselling-style services, particularly if available in accessible locations as soon as help is needed, are often preferred by young people using mental health services (Youth Access, 1994; Laws, 1998; Neill, 2003; Sherman-Jones, 2003; Svanberg and Street, 2003; Street et al, 2005). Healey also reports widespread support among secondary school pupils for counselling services or peer support services in schools, with nearly nine out of ten respondents thinking it was a good idea. In practice, however, many pupils appeared to have reservations about using such a service; victims of bullying, for example, tended not to seek help rather than go to see a counsellor.

The shortage of counsellors can be a problem for particular groups of children and young people. Clarke et al (2005), for example, report that young people who have cancer often cannot get access to counselling support services.
POSTSCRIPT

If asked, children and young people are well able, and usually willing, to provide views on their health as well as their personal experiences and requirements of health services. The kernel of their message is well and poignantly encapsulated in the following poem printed at the beginning of Listening, Hearing and Responding, the Department of Health action plan for consulting children on health matters.

My Rights as a Child are
To have someone I love with me wherever possible
To be told what is happening to me
To ask questions and be given answers I understand
To not be alone if I am sad
To be able to play even if I have to stay in bed
And....
That people are honest with me
That the people who care for me understand children’s needs
That I am safe, that my body is my body
That I am respected as a real person with feelings and rights of my own
That my well-being is the most important thing
And I am part of a family

[DH note: This poem originally appeared in the journal Maternal and Child Health and is reproduced here with kind permission of Manukau Health, New Zealand. This poem is also produced as an Introduction to the NHS Estates document, Friendly healthcare environments for Children and Young People.]

The overall conclusion of this review is that there is strong evidence that children and young people have been widely consulted about health matters, as well as good understanding of what they see as optimal health services. There is also now extensive guidance on good practice, and clear directives for local services to consult young people about their own health care. The way forward is to act on the key messages that emerge from the evidence (as summarised at the beginning of this report), and to create incentives to ensure that directives for improved provision are followed. Many health services are much more friendly towards children and young people than in even the recent past, but there is still no room for complacency.
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