Listening to children's views on health provision

A rapid review of the evidence

Ivana La Valle and Lisa Payne with Jennifer Gibb and Helena Jelicic

National Children's Bureau: working with children, for children

Registered Charity Number 258825.
8 Wakley Street, London EC1V 7QE. Tel: 020 7843 6000

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Contents

Acknowledgements 3
Foreword 4
Executive summary 5
1. Introduction 11
1.1 Policy background 11
1.2 Aims and scope of the review 12
1.3 Methodology 13
1.4 Report outline 14
2. Physical health 16
2.1 A health service designed by older people for older people? 16
2.2 The experiences of vulnerable groups 20
2.3 How health provision could become more child friendly 24
2.4 Summary 30
3. Mental health 32
3.1 Children and young people's views on mental illness 32
3.2 Children and young people's experiences of mental health services 33
3.3 The experiences of vulnerable groups 36
3.4 How could mental health services become more child friendly? 40
3.5 Summary 42
4. Being healthy 44
4.1 Views and concerns about public health 44
4.2 Views and concerns about specific public health issues 46
4.3 The experiences of vulnerable groups 49
4.4 How public health services could be improved 50
4.5 Summary 51
5. Shaping national policy and local services 53
5.1 Children and young people's involvement in health policy 53
5.2 How involvement can lead to change 56
5.3 Views of being involved in service development 58
5.4 Summary 59
6. Conclusion 60
6.1 Making the NHS more child friendly: learning from existing evidence 60
6.2 Making the NHS more child friendly: filling the evidence gaps 61
6.3 Making the NHS more child friendly: key policy messages 62
6.4 Final thought 63
Appendix A Respondents to the call for evidence 64
Appendix B Details of search strategy 68
References 69

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Foreword

The reforming NHS and public health service has the opportunity, one that may not occur again in the next 60 years, to weave throughout its emerging processes and structures the voices, views and experiences of children and young people, building on the established practices of involving adults individually and collectively. The NHS Mandate, the NHS and Public Health Outcomes Frameworks, commissioning processes and delivery contracts, Health and Well-being Boards and HealthWatch can all engage directly with children and young people. Children and young people can have a positive influence right through to their place within clinics and during treatment. These are all routes to building a 'whole population' health service in England. The Government has risen to the opportunity to improve children and young people's health outcomes and their experiences of health services. This review, which provides a comprehensive and up-to-date picture of children and young people's views on their health and healthcare, highlights some important lessons that national policy makers and local planners should use to ensure that children and young people receive a higher priority in the NHS.

Barbara Hearn, OBE
NCB Deputy Chief Executive

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Executive summary

This rapid review was carried out by the Research Centre at the National Children's Bureau (NCB) on behalf of the Children and Young People's Health Outcomes Forum[1]. The review provides a synthesis of up-to-date evidence on children and young people's views and experiences of health provision. At the time when the Government is taking forward a major programme of reform of the NHS and public health service, this review can provide valuable learning on how health services can improve to better meet the needs of its younger users.

About the review

The review involved the search of academic data bases and a 'call of evidence' to gather examples of local and national consultations with children and young people about health issues. We identified 112 relevant documents (66 research studies and 46 consultations), which were included in the review.

The review includes evidence from England and from the past five years (i.e. from 2007 up to end of January 2012). It focused on the views on health issues that are important to children and young people and their experiences of health services. The review explores children and young people's views and experiences of physical and mental services, of public health issues, and their involvement in health consultations. The findings emerging from the review are used to highlight a set of recommendations on how the NHS needs to change to meet the needs of its younger users.

Physical health

By and large under 16 year olds are excluded from national health surveys exploring NHS users' satisfaction. The rare surveys that included children and young people showed high levels of satisfaction with various aspects of health care, but on the whole they were less likely than older NHS users to report positive experiences (Hargreaves and Viner 2011). Furthermore a number of smaller scale studies and consultations have highlighted some consistent themes in relation to children and young people's experiences of primary health and hospital care (Kelsey, Abelson-Mitchell et al. 2007; Shaw, Southwood et al. 2007; Aldiss, Hortsman et al. 2009; Gibson, Pearce et al. 2009; Moules 2009; Hopwood and Tallett 2011):

[1] The Forum was established by the Department of Health in February 2012 to oversee the production of a child centred Children and Young People Outcomes strategy.

- **Poor communication from health staff** who tended to communicate with parents and spoke in a way that children and young people could not really understand.
- Health staff were reported to be **unfriendly and not treating them with respect**. However, this was not a universal experience, children and young people also talked about staff being nice, helpful, kind, comforting and caring.
- **Failure to consistently involve children and young people in decisions about their care** is a key theme emerging from the evidence. But the review has also shown evidence of positive outcomes when children and young people were listened to and played an active role in the management of their care.
- Positive views were expressed about experiences of child friendly children's wards and clinics (e.g. brightly coloured, with age appropriate activities and toys). However, being cared for in **unsuitable and unwelcoming environments** was another recurrent theme emerging from the evidence, particularly, but not exclusively, reported by young people transferring to adult services.

The experiences of **vulnerable groups** by and large reflected those reported above. However, some of the difficulties could be amplified, for example:

- **Communication difficulties highlighted above could be even more severe** for children and young people with speech, language and communication needs if health staff did not know how to communicate with them (Beresford, Rabiee et al. 2007; Watson, Abbott et al. 2007; Sloper, Beresford et al. 2009).
- Studies of young people with long term conditions (e.g. diabetes, asthma) highlighted how **they could get 'lost' during the transition to adult services**. However, the transition, **if properly managed and supported, could represent a positive experience** (Kirk 2008; Wray and Maynard 2008).
- For children and young people who **lacked parental support** (e.g. in care or secure accommodation) a key issue was the **lack of information and advice** on health issues and accessing health services (Cameron 2007; Cafcass 2008; Chase, Knight et al. 2008).

Mental health

Many of the experiences reported in relation to mental health were similar to those emerging in relation to other health provision. While there were some positive experiences, contact children and young people had with mental health

services could be characterised by (Chase, Knight et al. 2008; Child and Adolescent Mental Health Services 2008; Lavis and Hewson 2010):

- A lack of respect
- Inadequate communication
- A lack of involvement in decisions that affected their lives
- A failure to be treated with dignity
- Inadequate placement in and transition to adult services
- Inappropriate placement in and/or badly planned transition to adult services.

The evidence also highlighted issues that were specific to mental health, namely (YoungMinds 2011):

- The **stigma** attached to mental illness, which could make it hard to ask for and access support
- The fact that mental health was seen as an **add-on rather than a mainstream service**.

Again the evidence shows that the mental health difficulties children and young people experienced could be amplified if they were in circumstances that made them even more vulnerable, for example, if they were in care, in the youth justice system or asylum seekers. Access to information about mental health services and support in accessing these services was particularly important for these groups (Chase, Knight et al. 2008; Naylor, Lincoln et al. 2008; Greco, Beresford et al. 2009; Berelowitz 2011; Summerfield 2011; YoungMinds 2012).

Public health

The review has shown that **children and young people acknowledged the importance of being healthy** and having a healthy lifestyle, but did not always feel they had access to the information and advice that would enable them to make healthier choices (Cameron 2007; Morgan 2010; Children's Society 2012). They realised that **advertising campaigns and peer pressures** could make it difficult for some to make healthy choices, and that those who lived in more deprived areas were at greater risk from those kinds of pressures (Gosling, Stanstreet et al. 2008; NCB 2008; Pearce, Kirk et al. 2009; ChaMPs 2011).

Children and young people believed that many **public health campaigns** were too obviously **designed by and for adults**, and failed to answer the questions they had about sensitive issues, such as sexual health (Counterpoint Research 2008; Young People's Public Health Reference Group 2008; Norfolk YOT 2009; Diva 2010; Innovation in Society Unit 2010; NCB 2011b). The evidence review also showed the **need for information to take into account the needs and views of vulnerable groups** (Davey 2008; Norfolk YOT 2009; West Bromwich 2011; NCB 2011a) and that children and young people are themselves a

diverse group, who need different kinds of information delivered in a variety of ways (NCB 2010b; Afiya Trust 2011; National Advisory Council 2011; NCB 2011b).

The evidence shows that children and young people were consulted about a wide range of public health issues (ChaMPs 2011; NCB 2011a; NCB 2011b), some of which were of critical importance to children and young people but also had **implications for other services**. For example, research and consultations on early sexual activity or tackling underage drinking, commissioned by health agencies, often included recommendations for more things to do in the local area and access to better public transport, but it was unclear whether these 'non-health' recommendations were taken any further (Young People's Public Health Reference Group 2008; Diva 2010; ChaMPs 2011).

The consultations reviewed clearly showed that children and young people want to be involved in (Cafcass 2008; Davey 2008; NCB 2008; Norfolk YOT 2009; NCB 2010b; Afiya Trust 2011; ChaMPs 2011; National Advisory Council 2011; West Bromwich 2011; NCB 2011a; NCB 2011b):

- Public health discussions
- The design, development and evaluation of child friendly campaigns and information
- The design, development and evaluation of local health services for children and young people.

These activities may be happening, and we received a number of examples, but on the whole **children and young people's contribution remains unrecorded and therefore impossible to measure**.

Shaping national policy and local services

The review provided some examples of local and national consultations with children and young people on health issues, and explored their views on these experiences (Great Manchester East Cheshire High Peak and Rossendale health care services 2007; National Advisory Council 2010; NCB 2010b; British Youth Council 2011; NHS North West 2011; NCB 2011a; NCB 2011b). These examples clearly showed that children and young people believed they **should have a say in decisions about their health** and be allowed to take a lead where they were capable.

While children and young people valued the support and advice of their parents and carers, they **had their own opinions** and wanted to be able to exercise their **own choices**. Most of all, they wanted to:

- Be listened to
- Have their recommendations acted on

- Be informed of what happens as a result of their recommendations
- Meet with decision-makers so they can explain why their recommendations may not have been taken on board.

Conclusion

Several lessons emerge from this review on how the NHS could meet the needs of its younger users:

- While **parents** are especially important for younger children as 'information providers', children and young people also want to be able to receive information directly from health staff.
- This information needs to be **child friendly** and explain what health services are available and how they can be accessed.
- Communication from health staff should be underpinned by **respect** and recognition of children and young people's right to be **involved in decisions** about their health and care.
- A **good relationship with health professionals based on trust and mutual respect** matters a lot to all children and young people, but is especially important for those receiving long term healthcare and using mental health services.
- Children and young people, like other NHS users, want health services which are effective, flexible, personalised and provided in **child friendly environments**.
- The **transition to adult services needs to be more carefully managed and planned** in collaboration with young people and their families.
- Responsibility for informing and supporting children and young people with health issues needs to go **beyond health professionals**, particularly for those who lack parental support (e.g. in care).

The review has identified major **gaps in the evidence**:

- The virtual exclusion of under 16 year olds from NHS surveys represents a large evidence gap that should be filled by ensuring that **NHS surveys** are based on **samples and child friendly methodology that adequately represent all NHS users**.
- Robust and regular research evidence is needed to establish to what extent **children and young people are consulted over a range of health issues and are able to see how their input is used to reform and improve the NHS**.

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The evidence highlights the need for **mechanisms to hear the voices of children and young people** to be embedded at every level of the system:

- In the work of local and national HealthWatch
- As part of Health and Well-being Board's assessment of local needs and development of a local health and well-being strategy
- In the commissioning decisions of the clinical commissioning groups and Directors of Public Health
- In the work of Public Health England
- In the day-to-day decisions of practitioners.

Alongside the direct involvement of children and young people themselves:

- **Children's service leaders** should be champions for children's health in local strategic partnerships.
- **Health Education England** should ensure that health practitioners are confident in communicating effectively with children and young people.
- **Clinical commissioning groups** must develop a good understanding of what a child-friendly service and setting look like, incorporating the *You're Welcome* standards[2] into commissioning decisions and contracts.
- Children and young people should be included in all relevant NHS patient surveys, and their experiences of services should be reflected in the **NHS and public health outcomes frameworks**.

Acting on the above evidence, nationally and locally, would reflect a commitment to giving children and young people higher priority in the NHS.

[2] The *You're Welcome* standards were published by the Department of Health in 2011 to define what constitutes good quality and accessible health services for young people (aged 11-19). The standards are based on examples of effective practice of working with young people and should be applied to health services and health promotion Department of Health (2011).

1. Introduction

This report is based on a rapid review of the evidence carried out by the Research Centre at the National Children's Bureau (NCB) on behalf of the Children and Young People's Health Outcomes Forum. The Forum was set up to inform the development of a strategy for improving children and young people's health outcomes. The review was commissioned to support the work of the Forum by gathering and synthesising the most up-to-date evidence on children and young people's experiences and views of health provision, and how health services can be improved to better meet their needs.

In this chapter we briefly set out the policy background for the review. We then outline the aims and scope of the review and how it was carried out, and conclude by providing a report outline.

1.1 Policy background

The Government is currently taking forward a major programme of reform of the NHS and public health service. The implementation of measures in the Health and Social Care Act 2012, and the associated NHS and public health white papers (Department of Health 2010a; Department of Health 2010b), will result in significant changes to the way health services are planned and delivered, and local services work together to improve health and well-being. GPs will take on the majority of NHS commissioning, local authorities will be responsible for public health services, and a range of local partners will work together to set a local strategy for health and well-being through new Health and Well-being Boards. At the national level, the NHS Commissioning Board and Public Health England will oversee their respective parts of the system. In these reforms the Government has emphasised patient and public engagement in decision-making about health services and individual care, recognising that effective patient involvement results in better health outcomes and greater satisfaction with services (Department of Health 2010a). HealthWatch England and local HealthWatch will be required to champion the voice of patients, and health planners and commissioners will be legally obliged to involve the public in decision-making. While these changes are due to come into force formally in April 2013, the majority of local areas are already implementing the reforms in preparation.

Children and young people are one of the NHS key stakeholder groups, for example, they account for around 40 per cent of the workload of a typical GP (Kennedy 2011). They are also a key target group for public health services that aim to promote good health in childhood and adolescence to prevent a greater demand on services in later life. However, children and young people

have not had a consistent voice in decisions about their care and the health services they use, and have been a disproportionately low priority in the NHS, compared with adults (Kennedy 2011). The Government has recognised that the proposed health reforms provide an opportunity to improve children and young people's health outcomes and their experiences of health services. In February 2012 the Department of Health established a Children and Young People's Health Outcomes Forum to inform the development of a strategy for improving children and young people's health outcomes. The Forum's brief is to advise Government on what outcomes should be expected of an effective health service for children and young people, and how the system can deliver those outcomes. The Forum has made listening to what children and young people say themselves about their health and health services a priority action, and commissioned this rapid review to inform its work.

1.2 Aims and scope of the review

The overarching aim of the review was to provide a picture of the extent to which children and young people, including those from vulnerable groups, are consulted about health issues and services, and the key findings and recommendations emerging from this evidence.

The review has covered **all types of health**, that is, physical, mental and public health. It has focused on the views on health issues that are important to children and young people and their experiences of health services, it does not include evidence of what professionals and parents think about these issues.

Due to time constraints the review focused on evidence from the **past five years**[3] (i.e. from 2007 up to end of January 2012) from **England**.

Children and young people were defined as those up to the age of 18, or 25 in the case of young people with a disability, a long term health problem, care leavers and young people in custody. We specifically searched for literature on a **wide range of vulnerable groups** - i.e. those with a disability, learning difficulties and long term health problems; ethnic minority groups; children in care and care leavers; those in custody and secure settings; asylum seekers and refugees; Roma, Gypsy and Travellers; those living in poverty; homeless; and, teenage parents. However, in the period we reviewed, we found limited evidence and only on some of these groups.

The evidence we reviewed falls into two broad categories:

[3] For a review on the same topic covering an earlier period see: National Children's Bureau (2005) Children and young people's views on health and health services - A review of the evidence. London: National Children's Bureau.

- **Research studies** where data was gathered directly from children and young people. We identified a very small number of studies based on large scale and nationally representative surveys, which provide robust statistical evidence (i.e. numbers) on children and young people's views and experiences[4]. Most research studies reviewed were small scale and qualitative, involving, for example, in-depth interviews, focus groups and unstructured observation. They provide an in-depth exploration of a range of experiences, views, attitudes and the factors underpinning these. They also illustrate how health priorities and services should be informed by children and young people's views and needs. However, qualitative studies cannot provide measures of prevalence of the issues explored.
- **Consultations** with children and young people carried out by health bodies, local authorities, and children and young people charities. We expected much of this information not to be easily identified through data base searches and some not to be in the public domain. Therefore we had a 'call for evidence' in February 2012. The list of those that responded to the call for evidence is included in Appendix A.

In reporting the findings, we have made it clear whether the evidence was based on research studies, designed and conducted in a way to give certain guarantees about the robustness of the data; or, from consultations, which could not strictly speaking be generalised beyond the groups consulted. For research studies, a basic assessment of the methodology was made by the research team (e.g. to distinguish between quantitative and qualitative research, give an indication of sample size and method), and this assessment was used to decide if and how this evidence should be presented.

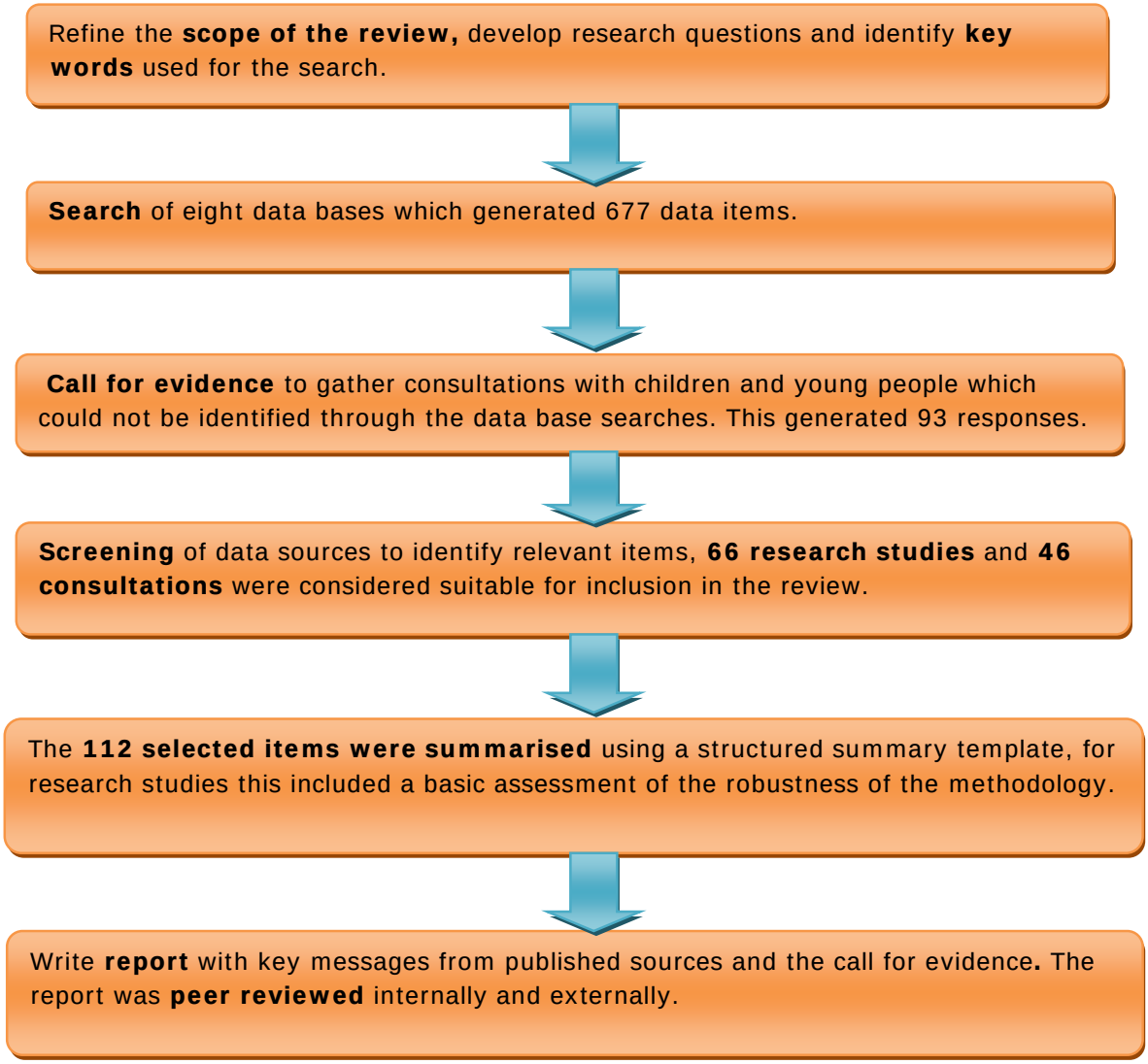
1.3 Methodology

The review involved the search of eight academic data bases, using the key words listed in Appendix B, which generated 677 data items (e.g. research reports, journal articles), largely based on research studies. The call of evidence resulted in 93 responses. Through the search of the academic data bases and the call for evidence we identified **112 relevant items** (66 research studies and 46 consultations), which were included in the review. To be relevant for the review, items needed to be based on information or data gathered directly from children and young people, and to focus on their views and experiences of health provision, and/or their views on priority for health services. More

[4] We only report actual statistics when surveys were carried out using a robust methodology (i.e. using probability sampling and achieving a good response rate) and when the results were reported to be statistically significant. A few of the surveys reported did not comply with these methodological standards, in these cases we give an indication of what the findings were, but do not provide actual numerical estimates.

detailed information about the review methodology is included Figure 1.1 and Appendices A and B.

Figure 1.1 Summary of review methodology



1.4 Report outline

In **Chapter 2** we explore children and young people's experiences of **primary health and hospital care**, and their views about these experiences. We then highlight recommendations for improving these health services emerging from the research and consultations reviewed.

In **Chapter 3** we focus on **mental health**. We start by discussing children and young people's views and attitudes on mental illness, and we then explore their

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experiences of mental health services. We conclude by highlighting recommendations for improving mental health provision for children and young people.

In **Chapter 4** we review the evidence on **public health.** We explore what 'being healthy' means to children and young people, their involvement in shaping the public health agenda, the kind of information that would support healthier life styles, and their recommendations for improving public health services.

As well as exploring overall findings on children and young people's views and experiences on the above topics, in each of the chapters we also consider the views and experiences of vulnerable groups.

In **Chapter 5** we look at children and young people's **involvement in health consultations** and any evidence that their involvement leads to improvement in services.

In **Chapter 6** we draw together the key findings from the review and the **conclusions** from the evidence reviewed.

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2. Physical health

In the first part of the chapter we explore children and young people's experiences of primary health care and hospital care, and their views about these experiences. We then discuss the experiences and views of groups who are more vulnerable because of their social circumstances. In the third part of the chapter, we highlight recommendations for improving health provision that emerged from the research and consultations we reviewed.

2.1 A health service designed by older people for older people?

Hargreaves and Viner (Hargreaves and Viner 2011) provide a comprehensive review of children and young people's experiences of health provision, based on 38 national health surveys undertaken between 2001 and 2011. The aims of the study were to establish if the views and experiences of children and young people (up to the age of 24) were explored in national surveys, and compare those with adults' views and experiences. The study highlighted a large gap in the research evidence used to inform health policy and provision, as well as lower than average satisfaction among young people. As the authors explain:

> *The views of under 16s and their families have largely not been included in national* [health] *surveys, contributing to less than 0.6 per cent of survey respondents since 2001 and none since 2004. Young people aged 16-24 are included in surveys, but they rate their care significantly lower than adults across all domains of emergency department and primary care, and most domains of inpatient care.*
>
> (Hargreaves and Viner 2011) p.4

The authors conclude that young people's lower satisfaction with health provision is consistent with other UK and international evidence:

> *These findings are consistent with a range of expert opinion and qualitative research with young people, supporting the view that that 'the NHS is designed by older people for older people'.*
>
> (Hargreaves and Viner 2011) p.5

Box 2.1 provides some of the key results from the study.

Box 2.1 Key results from a review of national health surveys

The study focused on survey findings on experiences of primary, inpatient and emergency care, and analysed four aspects of care: feeling involved in care; having confidence and trust in the doctors; being treated with respect and dignity; overall satisfaction with care. Overall the survey found that satisfaction levels among young people (aged 16-24) were high, but in most cases lower than those reported by older users.

- In the Emergency Department Survey, the experience of 16-24 year olds was significantly poorer on all aspects of patient care explored, compared with older respondents.
- In the Inpatient Survey young women aged 16-24 were significantly less likely than older patients to report a positive experience on all four aspects of care reported good care. Young men aged 16-24 reported a less positive experience than older men on all measures of care expect for perceived involvement in care.
- In the Young Patient and Adult Inpatient Surveys which included children (i.e. under the age of 12), found that both children and young people (aged 12-17) had less confidence and trust in doctors than older respondents. The picture is more mixed in relation to other aspects of care. For example, male children and young people were less likely to say that they had been treated with dignity and respect than older male respondents, but female children were more likely to report a positive experience in relation to this than older female respondents.
- The GP Patient Survey showed that the experience of primary care for 18-24 year olds was significantly poorer than for older adults across all the measures analysed.
- Perceived involvement in care was higher in 12–17 year olds than in adults, while there was no significant difference between children under the age of 12 and adults.

(Hargreaves and Viner 2011)

Other smaller scale research studies reviewed do not provide a comparative perspective with adults' experiences and views, but they highlight some common themes in relation to children and young people's experiences of health provision.

A small qualitative study with 12-16 year olds who had been hospitalised, used vignettes to explore their views on what they considered to be the most important aspects of care, and their experiences in relation to these i.e. what were the best and worst aspects about the care they had received (Moules 2009). The most important aspects of care reported were:

- **Technical expertise**: some respondents saw aspects of poor technical expertise as being on their list of 'worst aspects of care', but there were also examples of good technical expertise on their 'best aspects' of care list.
- **Explanations from health staff**: girls were more likely to report 'missing explanations' and health staff not communicating with them but only with their parents. On the more positive side, one respondent stressed how good it felt when doctors spoke directly to him about his care.
- **Choice**: participants reported instances of choice being given as 'best' aspects of care, they said they did not like being told what to do and appreciated being asked what they wanted. Young people also acknowledged that they did not always know what was best for them and that choice was not always possible or appropriate.
- **Friendly staff**: participants noted when staff were friendly or unfriendly. They talked about staff being nice, helpful, kind, comforting and caring. They disliked it when staff gave the impression that they did not want to be bothered.
- **Respect**: young people picked up on lack of respect in the vignette, they talked about 'being treated like I was stupid', being ignored, or being patronised.

A national survey of hospital patients aged 8-17 found that overall the overwhelming majority were positive about their experience, with 96 per cent saying that they had been looked after well or fairly well. However, results on more specific aspects of their experience showed a less positive picture (Hopwood and Tallett 2011):

- Six in ten respondents felt that there were not enough age-relevant activities to do when waiting to be seen
- Just over half were not fully aware before the appointment what would happen at the appointment
- One in three said doctors did not speak to them in a way they could fully understand
- Just over a third said they were not fully involved in decisions about what happened to them during their appointment
- A quarter felt that they were not given enough privacy when being treated or examined.

Poor communication, lack of appropriate facilities and involvement in decisions affecting their care were also recurrent themes in the consultations reviewed. Below are some quotes from a consultation carried out by peer researchers with children and young people (aged 12-19) with learning disabilities on **what it is like to go to hospital** (West Bromwich 2011):

A qualitative study with hospitalised 13-16 year olds provides an in-depth exploration on their involvement in the management of their care (Kelsey, Abelson-Mitchell et al. 2007). On involvement in **decision-making** the study found:

- Young people reported different levels of involvement in their care: most often they said they were fully in charge, sometimes they shared decisions with others, and sometimes decisions were taken (or necessarily constrained) by expert health professionals and by parents.
- They recognised limitations on their ability to make decisions when feeling unwell, and appreciated support in these situations, including accepting that others may have to take decisions on their behalf.

On the **impact of involvement** (or the lack of it) in decision making, the study found that:

- Being informed and involved was described by the young people as helpful because otherwise they would have felt more worried and anxious.
- Being given information and explanations helped young people feel included in decision making about their care.
- Effective communication at an appropriate level was important. In cases when staff only spoke to the young people to *obtain* rather than provide information, or just spoke to a parent, young people felt less in control, less able to trust carers, and more upset.

Qualitative studies of children and young people with cancer have also highlighted the link between **involvement in the management of care** and positive outcomes. For example, one of these studies concluded that listening to young people and taking them seriously was of great importance in avoiding

diagnostic delay and negative psychological effects (Gibson, Pearce et al. 2009). Another qualitative study of children and young people with cancer concluded that a high level of involvement in their care in childhood and adolescence prepared them to make informed decisions about their treatment and other health choices in adulthood (Gibson, Aldiss et al. 2010).

Research with young children shows the importance of **play and having parents around**. A qualitative study with four and five years old from an oncology centre reports that children talked a lot about the importance of having lots of toys to play with and to have parents in the hospital with them. Play specialists and play staff had an important role and children remembered their names and activities they were doing with them, whereas they did not remember the names of nurses (Aldiss, Hortsman et al. 2009).

The importance of parents is highlighted by another study involving a wider age range (4-19) of children and young people with cancer. As well as reporting the importance of having parental support and parents staying with them, this study also highlighted the key role parents played in relation to communication. The findings showed that communication about health and treatment occurred mainly within the family: **parents** were seen as '**information providers'**, whereas **health professionals** were seen as '**information dictators'** towards children and young (Gibson, Aldiss et al. 2010).

While children and young people clearly see their parents as playing a very important role in the management of their care, research has shown that **parents' and their children's views** of the care the latter receive **may differ**. For example, a study of adolescents with juvenile idiopathic arthritis, carried out to develop a transitional health care satisfaction scale, found that their satisfaction ratings were higher than those reported by their parents (Shaw, Southwood et al. 2007).

2.2 The experiences of vulnerable groups

In this section we focus on children and young people who are particularly vulnerable because of their social circumstances, these include: those with a disability, learning difficulties and long term health conditions[5]; children in care or leaving care; those in secure settings, custody and young offenders; and asylum seekers. This is not an exhaustive list, but just a list of studies and consultations with vulnerable groups identified by our review in the period

[5] Long term conditions include a range of conditions that can be managed but often not cured, such as diabetes, arthritis and asthma, or a number of cardiovascular diseases. To this we can add conditions such as HIV/AIDs and certain cancers, which have not traditionally been considered long-term conditions but which are increasingly experienced and regarded as such http://www.kingsfund.org.uk/topics/longterm_conditions/longterm.html

covered (i.e. 2007-January 2012)[6]. Research on the health experiences of these vulnerable groups highlights many of the issues already discussed in the previous section around involvement in decision making, respect, communication with health staff, the role of parents and carers, suitability of the environment. However there were also a number of issues that were specific to some of these groups.

Children and young people with a disability, learning difficulties and long term health conditions

A number of common themes emerged from the research with children and young people with a disability, learning difficulties and long term health conditions.

Children and young people (aged 6-24) with complex health needs[7] included in a qualitative study said they wanted the same things as other young people – friends, sex, money, a place of their own and the freedom to do things they enjoy – but the **way health services were delivered could be a barrier to achieving their aspirations** (Marchant, Lefevre et al. 2007).

The same study also highlighted the **range of stressors** faced by children with complex health needs, including: lengthy hospitalisation and the separation from family, friends and community; insufficient opportunities to have time alone with friends; restrictions on ordinary leisure and recreational activities; pain and fear from their condition and healthcare interventions; stigma, discrimination and prejudice. Yet the study found that children and young people appeared to have few outlets or opportunities to describe and express the discomfort and distress they experienced (Marchant, Lefevre et al. 2007).

For children with speech, language and communication needs some of the issues discussed above around lack of communication with health staff were even more severe when **staff did not understand how to communicate** with them (Beresford, Rabiee et al. 2007; Watson, Abbott et al. 2007; Sloper, Beresford et al. 2009).

The **transition from children to adult services** was explored by a qualitative study of 8-19 year olds with complex care needs (Kirk 2008), which found that:

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[6] It is particularly worth noting that we found very limited evidence on children and young people from ethnic minority groups. While this may partly reflect an evidence gap, it may be partly due to the reference period covered by the review, as evidence on these groups may have been mainly prior 2007.

[7] The term "complex health needs" can include children who are disabled, children with special educational needs and children with life-limiting or life threatening conditions. http://www.londondevelopmentcentre.org/children-families/disabled-children/complex-health-needs.aspx

- Formalised **transition planning appeared to be absent** and the transfer could come as a shock, although some participants reported that transfer to adult services had been discussed during an educational review meeting or a consultation with a community or hospital pediatrician.
- Young people had concerns about the **continuity of support packages** into adult services.
- Young people in the midst of multi-agency transitions spoke of **being in 'limbo'** as they were uncertain about where to seek support from and confused by the different age points for transfer used by different services.
- Young people in adult services described how they had needed to adjust to a **different culture or 'world'**. Adult hospitals were described as threatening and depersonalised, gloomy and dingy in comparison with the brightly coloured children's wards and clinics.
- Young people spoke about their **feelings of loss** as relationships with trusted professionals (e.g. nurses, play therapists) had come to an end.
- Young people found that **professionals in adult services treated them quite differently**, talking to them directly as adults and encouraging them to get involved in decision-making.
- Following the transfer to adult services, young people had to adjust to directly managing the service system (e.g. going alone to appointments, staying in hospital by themselves). These **new responsibilities could be acquired suddenly** on transfer to adult services and not as part of an integrated self-care transition process.
- Young people generally described **professionals as playing a peripheral role in relation to their transition from parental care to self-care**. However, support workers with the relevant expertise who provided support in a flexible, person-centred way were seen as giving young people an opportunity to experience an independent social life.

A qualitative study of 17-20 year olds with congenital cardiac disease also showed mixed experiences in relation to transfer to adult services. Young people in this study found that, compared with children's services, communication was better in adult services, they were kept informed about their care, doctors were easy to talk to and health staff talked to them rather their parents. They also liked some environmental aspects of the adult ward, including having en-suite room and less noise as there were no small children. Negative aspects of adult services included being with older people and feeling 'out of place' (Wray and Maynard 2008).

The above research findings are also reflected in a recent report by the Care Quality Commission which has reviewed how the health care needs of disabled

children and young people are met by health commissioners and providers (Care Quality Commission 2012)

Other vulnerable groups

We found very limited evidence from the period reviewed on the experiences of other vulnerable groups. We therefore can only provide some examples of issues that emerged, rather than a comprehensive overview.

A study by the Children and Family Court Advisory Support Services (Cafcass) on **care leavers**' health and well-being involving a small scale survey (i.e. 93 respondents aged 12-21) and more extensive qualitative research (i.e. 25 focus groups) identified difficulties relating to young people being in care. Research participants reported a lack of information on health issues, particularly relationships and sexual health (these are discussed further in Chapter 4). They felt they were not getting the right support and guidance from their carers, for example, in relation to healthy life style, sex and sexual health (Cafcass 2008).

A qualitative study of **care leavers** (aged 17-24) explored their experiences and views of primary and hospital care. These young people were very critical of GPs because of their perceived medical incompetence and lack of social skills. They also reported not been listened to by medical staff and getting treatments they did not want or need. There were criticisms of receptionists who were perceived as hostile and of delays before seeing a doctor or a practice nurse. Some experienced good relationships with doctors or practice nurses, these tended to be young people who had a regular consultation with a single practitioner, but being able to do so was not a typical experience because of frequent housing moves. In relation to hospital care, again young people felt that staff did not always credit the young person's judgment, but on the whole they had more positive views on this service. Overall positive views were associated with services that were accessible and staff who were polite, helpful, understanding, and went further than they had to by giving extra information, 'stopping to talk' or making young people comfortable when injured (Cameron 2007).

There is a regular survey of young people's perceptions of and conditions in **custody** which covers health. The most recent survey carried out in 2010-11 included 1052 young men aged 15-18 and 40 young women aged 17-18. The main survey results are reported in Box 2.2 (Summerfield 2011).

Box 2.2 Findings from survey of young people in custody

- 61 per cent of young men and 87 per cent of young women had had a full health assessment the day after their arrival in custody.
- Of those who had received the health assessment, 61 per cent of the young men and three quarters of the young women reported that the overall quality was good or very good.
- 72 per cent of young men said it was easy to access a nurse, 52 per cent a doctor, 32 per cent a dentist, 26 per cent a pharmacist and 24 per cent an optician.
- 85 per cent of young women said it was easy to see the nurse, 60 per cent a doctor, 39 per cent a dentist, 32 per cent a pharmacist and 21 per cent an optician.

(Summerfield 2011)

Finally we identified a qualitative study of **young people** (aged 12-23) **seeking asylum on their own**, which explored in considerable depth health issues and support. Most of the findings from this study relate to mental health and are therefore reported in Chapter 3, the findings on their primary care show their experiences were mixed. Some young people reported difficulties in registering with a doctor, and when they managed to see a doctor they were frustrated because they believed that GPs did not listen to them. Some were frightened to talk to GPs about their difficulties (e.g. sleeping problems in case they were prescribed drugs they might become addicted to), felt unable to talk to GPs about anxieties or other distressing feelings, or felt there was no point as they did not know what the GP could do to help. There were also positive experiences with GPs who had referred them to counselling, or respected their wishes not to take medication (Chase, Knight et al. 2008).

2.3 How health provision could become more child friendly

In this section we focus on conclusions and recommendations on how health provision should change to meet the needs of children and young people. We first provide a more general overview of how health provision and health professionals could improve. We then focus on recommendations and conclusions from evidence on vulnerable groups.

Improving health provision

Robinson provides a comprehensive overview of what children and young people want from health provision and health professionals based on a review

of 31 research studies carried out in 2000-2009, some of which were discussed earlier on. The study identified what children and young people see as key features that health professionals and the health service need to have to meet their needs (Robinson 2010), that is:

- **Familiar, accessible and available**: it is very important for children and young people that health professionals are familiar and can be trusted.
- **Informed and competent**: children and young people want to be cared for by professionals with the appropriate knowledge, expertise and competence.
- **Provide accessible information**: children and young people want professionals to provide information in a format that is accessible to them.
- **Good communicator**: children and young people want to understand what professionals say, they want to be listened to, valued and spoken to in a straightforward way.
- **Allow active participation in care**: children and young people want to be active partners in their care, and want to be able to express their own views and needs.
- **Privacy and confidentiality**: a recurrent theme in the studies reviewed was a concern about privacy and confidentiality and the need to be reassured that these will be respected.
- **Acceptance and empathy**: children and young people do not want to be judged by health professionals, instead they want to be treated with respect and dignity.

The research findings reported above reflect many of the recommendations from consultations with children and young people commissioned by the Department of Health in 2008 to inform the health strategy and in 2011 to inform health reforms (NCB 2008; NCB 2011a). They are also in line with the findings of a recent consultation commissioned by the Office of the Children's Commissioner (UK Youth Parliament 2011).

The Department of Health (DH) revised criteria for what constitutes good quality and accessible health services for young people (aged 11-19) also reflect many of the research findings discussed above (Department of Health 2011). The *You're Welcome* criteria (listed in Box 2.3) are based on examples of effective practice of working with young people and should be applied to health services and health promotion.

Box 2.3 *You're welcome* criteria

- Accessibility: ensuring services are accessible to young people and barriers to access are identified and removed.
- Publicity: need for effective publicity to raise awareness of the services available and the fact that these can be accessed confidentially.
- Confidentiality and consent: ensuring that young people are aware that they will be treated in confidence, and of the limit of confidentiality linked to safeguarding.
- Environment: ensuring that the health environment and the atmosphere (e.g. staff's attitudes and actions) are young people friendly.
- Staff training, skills and values: staff need to receive appropriate training and supervision in understanding, engaging and communicating with young people.
- Joined-up working: where possible co-locate services for young people, and when that is not feasible ensuring that other relevant professionals are informed about the service young people have received.
- Involvement in the monitoring and evaluation of the patient experience: young people need to be routinely consulted about current service, service development and reviews of service provision.
- Transition: the need to consult young people on transition issues, both universal ones (e.g. sexual and reproductive health) as well as those specific to young people with specific long term needs.
- Specialist child and adolescent mental health services (CAMHS): ensuring that the standards above apply to CAMHS services as well.

(Department of Health 2011)

Children and young people with a disability, learning difficulties and long term health conditions

The findings from research with children and young people with a disability, learning difficulties and long term health conditions reflect many of the recommendations discussed above.

The qualitative study of the **children and young people with complex health needs** discussed earlier provides comprehensive recommendations based on what the study participants reported (Marchant, Lefevre et al. 2007):

- Children and young people had strong views about who should provide the high levels of support they needed to stay well. Many wanted their **family to carry out most of their care** (albeit with training and guidance from

professionals). Some wanted their friends to help too – but there were mixed views on whether paid helpers were (or should be) friends.

- **Continuity and familiarity with health professionals** mattered, children and young people valued relationships with people who had known them for a long time and understood their needs.
- Children valued people who were **kind, thoughtful and warm**, and who took an interest in their lives.
- Older young people in particular talked about **dignity and respect**. They did not want personal information 'blabbed' to others. They value being able to share their thoughts, feelings and experiences safely with health staff.
- Children and young people valued the **clinical competence** of those who were meant to support them. This related to technical skills (e.g. school staff could help them in an emergency), but also confidence (e.g. staff who were calm and not 'stressy').
- Children and young people asked for **flexible and responsive support**, which could be tailored to their individual needs and give them a sense of personal autonomy and control.
- Many children said they hated hospital and **wanted to be supported at home** if possible.

Kirk's study of children and young people with complex health needs (Kirk 2008) and Wray and Maynard (Wray and Maynard 2008) research on young people with congenital cardiac disease provide similar recommendations, as well as some specific recommendations on the **transition to adult services**. In relation to the latter, the authors recommended:

- **Person-centred, multi-agency transition** planning is particularly important for young people with complex healthcare needs.
- **Intermediate services** that cross children and adult service cultures may be an appropriate way of organising services in some cases.
- There is a danger that professionals are too focused on service transfer rather than on this as one **element of a young person's move to adulthood**. Viewing it in this way would enable the transfer to adult services to be seen more positively.
- Young people need **support around ending long-term relationships** with professionals.
- Young people need to be **better prepared prior to the transition** in order to become progressively more involved in decision making and in

consultations with professionals, and responsible for elements of service organisation.

- Access to the support of **independent advocates** may be appropriate in some cases.
- **Separate facilities for adolescents**, which can provide activities appropriate for young people (e.g. computers, internet access, play stations, appropriate magazines).
- The need for **enhanced family visiting** when moving to adult services.

A consultation carried out by the Council for Disabled Children with **disabled young people** (aged 15-21) on their involvement in planning and managing their own health care provided detailed recommendations (see Box 2.4) which reflect many of the research conclusions discussed above.

Box 2.4 Recommendations from a consultation with disabled young people

- The development of an NHS e-learning module on communicating with young people with learning difficulties and communication impairments.
- The development of resources to address communication with disabled young people in hospitals.
- Health trusts should consider building protocols into the system for setting up appointments which would support preparation for the consultation.
- As the young person reaches adolescence, the clinician should explore with the family the formal handing over to the young person of their own diagnosis.
- At the stage of discharge from tertiary care after diagnosis, thought must be given to the way in which care packages impact on family life and ensure that they do not dis-empower families or young people.
- Performance assessments for staff working with disabled young people and those with long-term conditions should include a focus on the extent to which they are fostering self-care and independence.
- Settings should ensure that protocols for the safe management of medicine maximise young people's independence and control around self-medication.
- Consultations with all health professionals must place the young person at the centre. Every effort should be made to enable children to make a contribution to the consultation and any decisions made should take into account any preferences expressed by the young person.

(Council for Disabled Children 2011)

Other vulnerable groups

In relation to **children in care**, the Cafcass report mentioned earlier concluded that, given carers' reported failure to provide advice and support on key health issues, a key objective for policy makers is to ensure that this group has accurate information and support on general health, as well as sex education, alcohol, drugs, healthy eating (Cafcass 2008). Cameron's (Cameron 2007) study of care leavers, reported earlier, concluded that in order to meet their needs health services need to offer anonymity, be trustworthy, reliable and accessible at convenience times and location. The author also concluded that to be effective health provision needs to be part of an open access service offering a range of support (e.g. education, training) under one roof.

Local consultations provide more detailed accounts of what kind of practical support **care leavers** would like. Again the need for better support and advice on a range of health issues and services are key themes emerging from these more detailed recommendations. Box 2.5 shows the recommendations from care leavers' own suggestions. Box 2.6 provides recommendations from a local consultation with care leavers carried out to address areas of improvement identified by the Care Quality Commission inspection report.

Box 2.5 Recommendations from care leavers

Increased levels of support

- More health services available to care leavers
- Regular check-ups (e.g. every 3-6 months)
- More money for dental/NHS doctor care
- Make sure all care leavers have a doctor, dentist and health visitors
- Ensure young people are settled and able to cope with managing their own care.

More information

- More advice and support on health issues, particularly on sex education
- Make health services better known and easier to get involved with, including sexual health clinics
- More information on how to register with doctors and dentists (the social workers need to take them and show them)
- Social workers need to be more aware of self-harm
- An education pack, newsletter or video on leaving care, so care leavers know how to use different health services.

(Goddard and Barrett 2007)

Box 2.6 Recommendations from local consultation with young people in care and care leavers

Guide to health services

- Where and how to find local health services, and how often young people should go to them (e.g. dentist)
- Information on health services needs to be clear about young people's entitlements (e.g. free prescriptions and dental care)
- How to get help if you have emotional problems
- Information on different types of contraception and where you can access them
- Information and services on giving up smoking, drugs and alcohol
- Information on how to eat healthily (e.g. what is a healthy 'five a day' diet and what is a bad diet and why)
- Information on free leisure passes, leisure facilities for children in care.

Health priorities

- Check-ups should be twice a year (even when you leave care) and should be up to 18 years of age and not stop at 16
- Carers should have more training on health
- Having the same health worker for health assessments, and ensuring that young people understand why they have the assessment and how they can benefit from it
- Confidentiality and knowing what is going to happen to young people's health information
- A health folder that has all young people's health information in it.

2.4 Summary

While the few health surveys that have included children and young people showed high levels of satisfaction with various aspects of health care, on the whole they were less likely than older NHS users report positive experiences. Furthermore a number of smaller scale studies and consultations have highlighted some consistent themes in relation to improving children and young people's experiences of primary health and hospital care. Most of the research

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studies and consultations reviewed show that children and young people expect:

- Care to be delivered by competent professionals who are able to effectively communicate with them
- To be involved in decisions regarding their care
- To be treated with dignity and respect by health professionals
- Information about their health and personal circumstances to be kept confidential
- To be cared for in environments which are appropriate to a child's age and needs
- Appropriate support and an efficient system for making the transition from children to adult services.

Many of the above recommendations are reflected in the *You're welcome* quality criteria developed by the DH and published in 2011 (Department of Health 2011). It remains to be seen if these quality criteria will have the intended effect and help service providers and commissioners to improve the suitability of health services for its younger users.

The review has also highlighted a fundamental flaw in the health planning process, as most of the survey evidence used to monitor satisfaction with health services (i.e. national health surveys) excludes the voices of those under the age of 16. Again *You're welcome* stresses the importance of capturing young people's experiences of health services, and it remains to be seen if the samples for these surveys will be extended to monitor the experiences of younger NHS users.

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3. Mental health

This chapter focuses on children and young people's views and experiences of mental health. We start by discussing their views and attitudes on mental illness, and we then explore their experiences of mental health services, including the experiences of particularly vulnerable groups. We conclude by highlighting recommendations for improving mental health provision emerging from the research and consultations we reviewed.

In the period covered by the review (i.e. 2007-January 2012), we found considerably less research evidence on mental health than on other health provision discussed in Chapter 2. Consequently this chapter relies more on consultations than research compared with the previous chapter.

3.1 Children and young people's views on mental illness

Some of the literature on mental health and children and young people focuses on their views and attitudes to mental illness. These can have important implications for the propensity to seek help, and how children and young people with mental health problems are viewed and treated by their peers.

A recent qualitative study with 10-18 year olds (who did not have mental health issues) found that (Lovett, Tamkin et al. 2011):

- Children and young people in the study considered mental illness to be a **stigmatising** condition associated with unpredictability, violence and 'deviation from normal behaviour'.
- They **confused learning difficulties with mental illness** (e.g. citing Down's syndrome as mental illness, or identifying struggling with reading/writing with mental illness).
- **Traumatic life events** were seen as potential causes of mental illness, as well as **inheritance and brain injury**.
- In terms of how mental illness affects people, the prevalent view was that it made people **behave differently** (usually being angry, dangerous or violent) and **unpredictably**.
- Most of their information about mental health issues mentioned by the research participants came from the **media** (e.g. soaps, celebrities) not from personal experience or people they knew.

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- When research participants **knew someone with mental health problems**, they tended to view mental illness as less serious, or an 'emotional problem'.
- The prevalent attitude to mental illness was **fear** (e.g. believing mentally ill people are unpredictable and dangerous). Children and young people were aware of stigma and **would not want anyone to know if they or a family member had a mental illness**, but also felt compassion, believing it was not 'their fault' if people had a mental illness.

A recent on line survey of 9-25 year olds (YoungMinds 2011) highlights age differences in relation to views and attitudes to mental illness. The survey results show that:

- Just over half of respondents believed that young people have mental health problems because they were born with them.
- Just under half said it was easier to tell someone if they did not feel physically well compared with feeling distress or unwell mentally. This was considerably more likely to be mentioned by older respondents (17-25 year olds) than younger ones (9-16 year olds).
- Those in their late teens and early twenties were more likely to know someone with a mental health problem, but they were also more likely to report negative associations with mental health. This seems to somewhat contradict the finding reported above that knowing someone with mental health problems is associated with seeing mental illness as being less serious.

3.2 Children and young people's experiences of mental health services

A recent study by the National Advisory Council, which included a review of existing evidence and a consultation with young people with mental health issues (their age was not provided), identified recurrent themes in children and young people's experiences of mental health services (Lavis and Hewson 2010). The study found that:

- Young people highlighted the importance of the relationships with practitioners. They need to **trust** the practitioner before they can talk openly about their problems, however, trust takes time to build and staff turnover, leave and shift patterns could obstruct this.
- Young people felt that they were **not taken seriously** and their problems were at times ignored until they were very unwell or in crisis, because

practitioners did not respond appropriately to their needs at an earlier stage.

- Problems could also escalate because young people **did not know how to access services** or because **services were not available**, some young people reported that they felt forced to create a crisis to get help.
- Some young people felt they were **not treated appropriately by health professionals and felt intimidated** by health practitioners. Young people thought many GPs lacked in understanding, awareness, empathy and interest, and were reluctant to provide certain types of support. When young people had been in hospital emergency admissions after self-harm or suicide attempts, at times they felt they had been treated as time-wasters.
- Young people expressed concern that they had to **tell many different practitioners about their problems**. They wanted local services to work together, improve communication and ensure young people were not passed around the system or discharged without support.

A national review of Child and Adolescent Mental Health Services (CAMHS) which involved a consultation with children and young people (and their families) found that difficulties they highlighted related to (Child and Adolescent Mental Health Services 2008):

- Frequent **staff changes and being passed between services**, which made it difficult to build trusting relationships with staff.
- **Not always being listened to and involved in decisions** about services and interventions received.
- **Insufficient information** to understand the help available from different services, referral procedures and contact arrangements for specialist services.
- Concern about **lack of early intervention and interventions which can stop suddenly**.
- The **availability of mental health services where and when they are needed** and co-location with other services to reduce the stigma associated with mental health provision.
- The need for **confidentiality** and information sharing protocols that reflect children and young people's views and their consent to share information.
- The need for **schools and colleges to provide information and support on mental health issues,** considerable variability was reported in relation to this.

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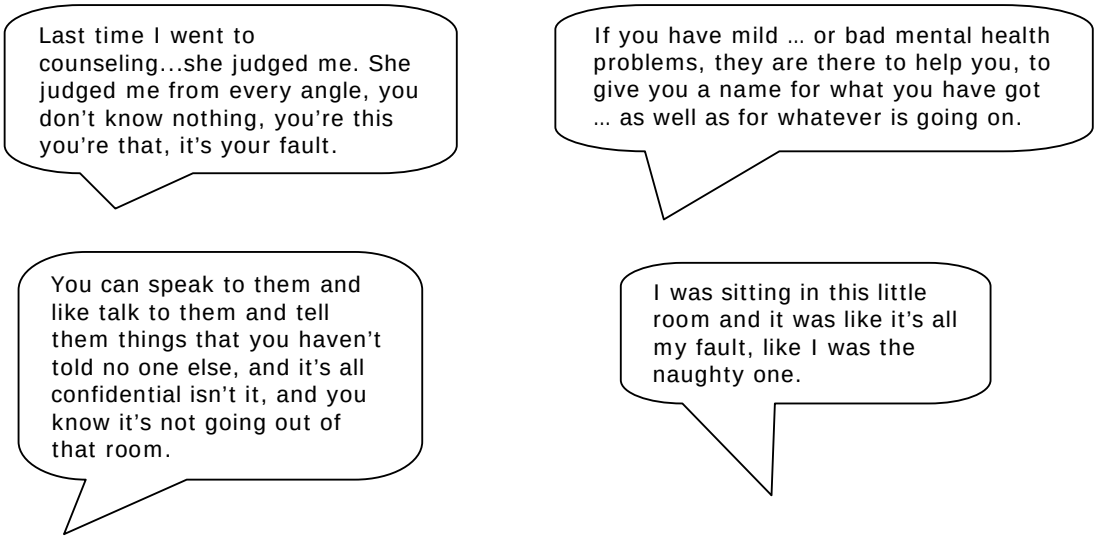
Research and consultations used locally to inform the development of CAMHS reflect some of the findings above, as well as highlighting other areas of difficulties. For example, a small qualitative study of young people (aged 13-17) who had used mental health services in Bradford (Rani, Prosser et al. 2009) found that:

- Young people sometimes felt that the quality of **information** given to them about the CAMHS, the illness and the treatment was **not adequate**. Some said that they could not take in all the information (e.g. emergency contact numbers) due to their emotional turmoil at the time it was provided.
- Young people reported that **contacting the team out-of-hours could be difficult** because the hospital switchboard seemed unaware of the nursing staff duty rota.
- Young people felt that a lot of support had been provided (e.g. lots of visits), but sometimes they were **not given the type(s) of support they really wanted**.
- They **valued home-based support** and being able to stay in their own environments, with their own food and routines, and appreciated not having to travel to receive support. They especially valued being able to keep in touch with friends and school.
- However, some young people were distressed by bad memories associated with their own homes, and this could make it hard to break a bad routine.

Below are some examples of what young people (aged 16-25) involved in a local consultation said about mental health professionals (Liverpool 16-18 Team 2008):



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As with other health services discussed in Chapter 2, the **transition from children to adult mental health services** could prove problematic if not properly managed or done at the right time. In 2007 the Office of the Children's Commissioner published a report to draw attention to the continued practice of admitting children and young people to adult mental health facilities (despite the national policy objective of ending such admissions) and highlight young people's experiences of these facilities (Office of the Children's Commissioner 2007). The report was based on a consultation with young people (aged 13-19) who had been in adult mental health services. Overall, the young people's experiences showed that, despite some positive developments, access to in-patient CAMHS remained problematic in many parts of the country and young people were still being placed on adult wards. When they were placed on adult wards, the level of care offered to young people was unsatisfactory, poorly planned and inadequately monitored.

A very small qualitative study of young people (aged 16-18) and their experiences of **moving to adult services** shows a lack of consultation with young people about the new service, which was not seen as appropriate for their needs (Day, Turner et al. 2007). Staff in both child and adult services were seen as not being able to communicate appropriately with young people. While CAMHS were seen as compassionate and flexible, young people in this study felt they had outgrown these services when they reached adolescence (e.g. they wanted to be able to talk to their worker and not draw pictures). Adult services were generally seen as supportive and understanding, but young people struggled to cope with its emphasis on the individual and independence. They wanted an 'adolescent sensitive' service within the adult service, rather than a third separate service, which would mean transitioning twice between different services. Support during the transition was also sometimes missing and young people suggested that a key worker or a GP could provide this.

3.3 The experiences of vulnerable groups

We looked at the experiences of children and young people, who, in addition to mental health problems, live in circumstances that make them more vulnerable. The evidence for the period we reviewed was limited so in this section we provide some examples of the experiences reported by some vulnerable groups, rather than comprehensive evidence on a wide range of groups.

A qualitative study of **children and young people** (aged 7-16) **who were deaf** and using specialist mental health services found that while they reported some positive experiences (e.g. liked their clinicians, felt supported and listened to, were able to communicate well with some clinicians who were able to use BSL or via interpreters), they also identified areas of difficulty. The latter included not having been given full information about the service and why it

was provided; communication difficulties with clinicians or interpreters using different signs; not being given sufficient reassurance about confidentiality; and, postponed appointments (Greco, Beresford et al. 2009).

Children in care are a group particularly likely to be affected by mental health issues, with 60 per cent having some level of mental health problem (quoted in (YoungMinds 2012)). A recent report by YoungMinds highlighted significant failures to provide adequate mental health support to this group. The qualitative study involved children and young people from residential homes, secure settings and foster care. The study found that young people were reluctant to talk about mental health issues and seek support because of the stigma associated with mental illness and negative perceptions of mental health services. As research cited earlier found, children and young people in this study also said they needed time to develop a relationship and learn to trust adults before they felt able to talk about their emotional well-being (YoungMinds 2012).

The regular survey of **young people in custody** mentioned in Chapter 2 found that 21 per cent of young men and 38 per cent of young women reported mental health or emotional well-being problems. However, only half of the young men and 69 per cent of the young women were receiving help for these problems (Summerfield 2011).

A qualitative study for the Office of the Children's Commissioner on the emotional well-being of **young people in the youth justice system** (Berelowitz 2011) found:

- Inconsistent practice and wide variation in type, level and quality of support with emotional well-being and mental health issues.
- Wide variation in staff's understanding of young people's mental health issues and services on offer to support them.
- Some professionals were very committed to providing adequate support with well-being and mental health issues, but they tended to work in isolation.

A qualitative study exploring experiences of a specialist mental health services for **young offenders and young people at risk of offending** shows very positive views and experiences of the service (Naylor, Lincoln et al. 2008). Sixteen out of the 20 young people who took part in the study felt the service had helped them to some extent, despite initial resistance to referral. Reasons for initial wariness included: anxiety about being labelled mentally ill; not wanting to talk to a stranger about something so personal; and, not knowing what would be involved or understanding why they had been referred. Five

factors were identified which helped practitioners engage young people and overcome resistance, these were:

- **A manner which demonstrates respect and commitment**: though not asked directly, young people said they appreciated their practitioner's manner towards them and might not have attended if they had disliked the worker or if the worker had not shown them respect. Feeling that the worker genuinely wanted to help also seemed important.
- **Being able to operate flexibly and offer outreach appointments**: some young people described their attitude to the service improving as their relationship with a worker developed through home visits and through the worker's effort to support them. Some young people mentioned valuing the fact that the worker accommodated their needs and preferences (e.g. home visits, some choice about dates for meetings and how long they went on).
- **Making therapeutic sessions seem personally relevant**: some young people described being convinced by the workers that the service was relevant to them or provided an opportunity to 'turn things around'.
- **Explaining clearly the role of the service**: young people who reported that the service had not been useful to them said they had not understood why they were being referred.
- **Clinical effectiveness**: experiencing positive effects from the service was an important influence on its acceptance and appreciation. Young people reported positive behavioural effects, including on anger management, and their ability to stop and consider the consequences of their actions. Some thought the service had helped them to stop offending, had improved family relations and communication with their family.

While this study has highlighted important features of an effective service from the perspective of young people, its largely positive findings seem out of line with most of the other evidence reviewed. It may well be that this was a particularly good service, but a 'social desirability' bias may have affected young people's responses, as interviews were mostly conducted in the building where the service was based. While the researcher emphasised confidentiality and his independence from the service, young people may have been guarded in their responses.

A qualitative study on the emotional well-being of young people (aged 11-23) **seeking asylum on their own** found that the support they received was not always adequate to meet their needs (Chase, Knight et al. 2008). The study found that:

- Some of these young people had had access to therapeutic services (including medication) and felt that they had helped them a lot to come to terms with their experience.
- Some had not been offered counselling, but felt they could have benefited from it, others received support but only after suicide attempts and wished this had been made available earlier.
- Some young people had refused counselling or other therapies. The author concludes that this was because the benefits of therapeutic mental health care had not been properly explained to these young people. In particular they were not presented in a way that avoided them feeling frightened or stigmatised.

Finally, a recent consultation has explored the mental health needs of young people from **ethnic minorities** and highlighted a lack of attention on the needs of this group (Afiya Trust 2011). The consultation involved young people (aged 12-24) from a range of ethnic backgrounds and included some for whom English was a second language, refugees and asylum seekers. Young people in the study identified a wide range of sources of sadness, worry and stress. These included:

- Relationships with family and partners
- Other people's negative behaviour
- Their own negative behaviour (e.g. smoking or taking drugs)
- Lack of employment
- Work-related stress
- Peer pressure
- Juggling differing demands of two cultures
- Illness and lack of sleep
- Insufficient money
- Pressures of education (e.g. exams, student fees, school admissions).

Few mainstream public services were mentioned as sources of support by these young people, who were more likely to rely on family, social networks and community organisations. Influences on the decision to seek help (and from whom) were:

- Knowing that confidentiality will be respected
- Trust in the person
- A good relationship
- Feeling at ease, understood and feeling safe with that person.

3.4 How could mental health services become more child friendly?

We saw earlier that many children and young people have negative views of mental health. To counter the **stigma** associated with mental illness and its consequences a recent research report (YoungMinds 2011) recommends that:

- Government should launch a 'mental health and well-being' promotion campaign aimed at children and young people to increase their understanding of mental health and how 'it is good to talk about how we feel'.
- Develop an evidence base to identify the most effective methods of influencing long term attitudinal change amongst children and young people.
- The equalities agenda should incorporate action on mental health discrimination.
- Professionals working with children and young people (e.g. teachers, youth workers, school nurses, GPs) must be trained on child and adolescent psychological development, mental health and the negative role that stigma plays in children's developing self esteem and in their ability to access support services.
- Teaching about good mental health and developing emotional resilience should be a central part of the Personal, Social, Health and Economic (PSHE) agenda in schools.
- Successful programmes that increase access to mental health support and services should be rolled out in schools.

Children and young people's recommendations for improving mental health services are provided in a report by the National Advisory Council, based a one year consultation with children and young people with mental health issues (Lavis and Hewson 2010). Young people who took part in this consultation argued that mental health services should be **mainstreamed**, that is:

- They should no longer be an add-on but a central part of all mainstream services for children and young people
- Staff in all agencies should be as confident in talking about mental health as they are about physical well-being
- There should be low key support, like physical health checks
- The new HealthWatch should focus as much on mental health issues as physical health.

Mental Health should be considered a **public health** issue and:

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- The NHS should raise awareness about mental health in the same way that it promotes anti-smoking and 'five a day'
- Health promotion in every school should include a major focus on mental health.

A range of other recommendations were also made by both the National Advisory Council report (Lavis and Hewson 2010), as well as the final report of the national CAMHS review (Child and Adolescent Mental Health Services 2008).

Children and young people should have the **right to a choice,** this would involve**:**

- Supporting them to understand the choices available and to make their own decisions; this would require appropriate advocacy
- Services ensuring children and young people know what their rights are and the full range of choices available to them
- Enabling them to express their views without labelling them as awkward or troublesome.

Children and young people should get support to make **informed decisions,** this would require:

- High quality, accurate child friendly information
- A language appropriate for the individual child
- Help and support from family or friends in making a decision, if the child wants these
- Taking into consideration what matters most to the child and not just a focus on symptom reduction.

Children and young people asked for an **accessible service** which is:

- Available when and where it is needed
- Available through the web, mobiles, email
- Outreach into schools and other agencies
- Based in the environment that works best for children and young people (e.g. home, clinic, a coffee shop)
- Flexible and tailored to individual needs.

Children and young people want a **high quality service**, this would require:

- Evaluations of services to show their effectiveness
- Not discharging young people as soon as the symptoms improve or stop the support when they turn 18
- Support for under- performing staff to ensure consistent outcomes for children and young people
- Sufficient numbers of trained staff to provide a good service
- Evidence that staff are able to form good therapeutic relationships and trust is developed with service users
- Services to put the needs of the young person first over processes
- Services to be adequately funded, and not reliant on short-term funding

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- National guidelines for children and young people's mental health to be as important as national guidance on the treatment on heart attacks.

Children and young people want to **have a say** in how services are delivered and developed, this would mean that:

- Their views would be taken seriously
- They would be told when their information is shared with other agencies, and wherever possible be involved in this decision
- Children and young people would be involved in supervision and reviews
- Ex-service users would provide feedback on service delivery and design at managerial level
- An evaluation framework with children and young people's voices at the centre
- Young service user feedback would be acted upon and progress would be fed-back to them.

Many of the recommendations above are supported by the research we reviewed (e.g. Garcia, Vasiliou et al. 2007; Lavis and Hewson 2010), by other national consultations with children and young people (e.g. Mental Health 2007; Office of the Children's Commissioner 2007), as well as local ones (e.g. (Liverpool 16-18 Team 2008; Nottinghamshire PCT 2008; Nottinghamshire PCT2 2009; Norfolk CAMHS 2011).

3.5 Summary

Many of the experiences reported in relation to mental health services are similar to those explored in Chapter 2 in relation to other health provision. While there were some positive experiences, contact children and young people have with mental health services can be characterised by:

- A lack of respect
- Inadequate communication
- A lack of involvement in decisions that affect their lives
- Failure to treat them with dignity
- Inadequate placement in and transition to adult services.

The evidence also highlighted issues that were specific to this type of health provision, namely: the stigma attached to mental illness, which makes it harder to ask for and access support, and the fact that mental health is seen as an add-on rather than a mainstream service.

We have seen that the mental health difficulties children and young people have can be amplified if they are in circumstances that make them even more vulnerable, for example, if they are in care, in the youth justice system or asylum seekers.

The themes underpinning the proposals for improving mental health services are again very similar to those discussed in Chapter 2. These highlight the need to:

- Improve professional competency and health professionals' ability to communicate with young users
- Ensure that children and young people are treated with dignity and respect
- Enable them to make informed choices
- Give them a say in the development and delivery of mental health services
- Tackle the stigma associated with mental illness and negative views of mental health services as these can be barriers to seeking help.

You're welcome, the Department of Health guidelines discussed in the previous chapter, should ensure that health services, including mental health provision, become young people friendly (Department of Health 2011). It remains to be seen if these guidelines will have the intended effect and help commissioners and providers in improving the suitability of mental health services to children and young people.

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4. Being healthy

This chapter covers public health issues identified as important by different groups of children and young people. The first part of the chapter focuses on three key questions:

- What does 'being healthy' mean to children and young people?
- Does their involvement in shaping the public health agenda matter?
- What kinds of information would support them to live healthier lifestyles?

As well as general findings on these questions, we also discuss the findings in relation to particular areas (e.g. alcohol, healthy eating, physical activity, sexual health) and vulnerable groups. Finally, we outline suggestions that children and young people made to improve public health services.

By and large research (and particularly survey series) collecting data from children and young people on health issues tend to focus on the prevalence of health problems and health behaviour. They do not typically ask about children and young people's views on the issues covered in this chapter, consequently most of the material cited in this chapter is based on consultations with children and young people.

4.1 Views and concerns about public health

What does 'being healthy' mean to children and young people?

In a research study of what contributed to their sense of well-being, children and young people (aged 7-16) identified a variety of key factors that covered different aspects of their lives: family, friends, activities, being safe, enjoying school (Counterpoint Research 2008). However, when asked what 'well-being' meant, they struggled to define it, but recognised that **being healthy was a basic part of being well**. The Children's Society's Good Childhood Inquiry explored in five surveys children and young people's understanding of well-being. In this research children and young people identified health, including their health behaviours, as a key component of their overall well-being (Children's Society 2012). For children in care, being healthy was top of the list when they were asked what contributed to their well-being (Morgan 2010). In one research study, a group of care leavers (aged 17-24) defined being healthy as comprising an absence of illness, emotional well-being, their living circumstances and social relationships (Cameron 2007).

Children and young people's identification and prioritisation of **public health areas can embrace a broad range of issues**. A consultation of young people aged 12-17 identified bullying, racism, self-harm, depression, stress, the home

and school environments as public health issues, which were seen as important as more typically cited areas associated with healthy lifestyles (Young People's Public Health Reference Group 2008). In another consultation, children and young people (aged 11-18) identified transport as the most important cross-cutting issue for their public health and well-being (NCB 2011b). As discussed in the previous chapter, Young Minds' National Advisory Council advocated seeing mental health as a public health issue, and recommended that the NHS raised awareness of mental health in the same way that it promoted anti-smoking or 'five fruit 'n veg' a day (National Advisory Council 2010).

Does children and young people's involvement in shaping the public health agenda matter?

Young people want to be asked about their health and about the health issues which are important to them – an issue that will be explored more widely in Chapter 5. In a consultation on the public health white paper (NCB 2011b), young people (aged 11-18) said that **engaging them in public health was essential** if they were to become healthy adults, and that they should be a priority for early interventions. They felt that there was insufficient attention paid to their health and well-being needs.

They wanted to continue to be involved at every level: in direct consultation with central government while the public health proposals were being considered; at national level through Public Health England; and at local level through the Health and Well-being Boards. They wanted their experiences to inform commissioning decisions, and be used as evidence to highlight young people's public health needs.

What kinds of information would support children and young people to live healthier lifestyles?

In a consultation on the public health white paper mentioned above, young people referred to the importance of being able to access interesting, engaging, accurate and high quality information that could help them understand how to be and stay healthy (NCB 2011b). When asked where they accessed health information, children and young people listed a number of sources, including: educational establishments, social and recreational venues, the media, family and friends, GPs and the internet, with a particular emphasis on social networking sites. Parents and carers in particular were reported to be an important source of information (NCB 2011a).

However, **schools are where the majority of children and young people received helpful information about public health issues**. For example, the TellUs survey found that two-thirds of young people in Years 8 and 10 reported receiving helpful information on healthy food and lifestyles in school

(Chamberlain, George et al. 2010). In another survey, children and young people appeared particularly well informed about the dangers associated with smoking, drinking and drugs, but wanted more emphasis on education around personal relationships and sexual health (Davey 2008). As such, schools must be considered as part of the health education and health information landscape.

Still, the evidence shows that straightforward information is not enough. **Health promotion strategies need to be tailored to individual groups and individual needs**. For example, a group of young people working with a Youth Offending Team (YOT) were consulted about alcohol use and offending. They wanted services to move away from an information loading model towards one built around discussion, interaction and reflection. They wanted tailored packages to allow for individuals to explore their thoughts and feelings – particularly when there were alcohol problems in the family or they had been involved in alcohol-related offending (Innovation in Society Unit 2010).

Another group working with their local YOT preferred face-to-face sources of information and help about health issues, rather than anonymous sources such as the internet and telephone helplines (Norfolk YOT 2009). When asked about sensitive issues such as mental health concerns, a group of black and minority ethnic young people said they wanted to access information confidentially and anonymously (Afiya Trust 2011).

4.2 Views and concerns about specific public health issues

In addition to the findings about general public health issues outlined above, the review has explored children and young people's views and experiences in relation to specific topics, that is: alcohol consumption, healthy eating, physical activity and sexual health. These are discussed in turn below.

Alcohol

In the period reviewed, research into ways to tackle **underage drinking** tends to focus on information and education (Williams 2011), and we therefore had to look at consultations to explore young people's views on why they drink. A consultation with young women (aged 12-19) in Cheshire and Merseyside found that they drank because of peer pressure and the ease with which they could get hold of alcohol from older friends, their parents or other members of the public (ChaMPs 2011). They believed they would be less likely to drink if they had access to more leisure activities; or received information that not only increased their awareness of the associated risks and harm of alcohol, but also of the effects it can have on a person's weight and image. They said that

increasing the price of alcohol was unlikely to have an impact on reducing the amount they drank.

Healthy eating

In general, both the research and consultation materials showed that the food children and young people eat is based on proximity and convenience, tastes and preferences, choice, social influences, parent/carer influences and familiarity (Pearce, Kirk et al. 2009). Advertising also has a considerable impact, although parents and carers mediate what children eat.

A research study found that although primary school children were critical of the **social acceptability of unhealthy foods**, the foods they held in high esteem were often those promoted through shrewd advertising (Gosling, Stanstreet et al. 2008). Food preferences were linked partly to taste, but also to social acceptability. Unfamiliarity with certain foods also held back children (and their families) from trying different things (Pearce, Kirk et al. 2009).

When asked in a consultation what they wanted the Government and others to do, children and young people recommended that **promotion of healthier foods, making them more affordable and providing free samples**. Some proposed banning shops from selling junk food (NCB 2008).

The evidence shows that food was especially important for children living away from home. A balanced diet, exercise and staff encouraging healthy eating was what they believed kept them healthy (Morgan 2009).

Physical activity

For children and young people the 'being healthy' aspect of physical activity and exercise is a by-product of playing, taking part in sports, or having fun. One group of primary school children included in a qualitative study **did not relate physical activity with health**, instead seeing it as part of their social lives and an important way to spend time with friends (Gosling, Stanstreet et al. 2008). These children lived in a deprived area of North West England and spoke about how a lack of space and local places to play impeded their ability to be physically active.

Another qualitative research study with primary school children found that the physical activities they engaged in were influenced by the proximity of relevant facilities, social and parental influences, safety, the quality of facilities available, familiarity with the area and local knowledge (Pearce, Kirk et al. 2009). Children from the more affluent areas knew about and used more of the local leisure facilities on offer.

The link the above consultations found between affluence and physical activity is confirmed by the research evidence which has consistently shown that levels of physical activity tend to be lower among children from less affluent families, with evidence showing this is related to parental influences (e.g. parenting skills, parents' life styles), but also environmental factors such as lack of safe places to play outside (Hansen, Joshi et al. 2010; Aldbridge, Parekh et al. 2011; Currie, Zanotti et al. 2012).

When consulted about support for healthy lifestyles, children and young people asked for **more local events, activities and sporting opportunities** (NCB 2008). In order to make best use of them, they said these activities and facilities need to be safe, accessible, affordable, welcoming and open during times they are most likely to use them.

Sexual health

Adolescence is the time when young people are beginning to explore their own physical and emotional development and sexuality. Its importance to young people is demonstrated by the number of times they mention their anxieties about sex education, sexual behaviour and sexual health issues when discussing wider public health concerns. It is a mix of wanting **more widely available, better quality and accessible local sexual health services**, and worrying about being labelled if they use them. For example, young people (aged 14-19) consulted in Nottinghamshire wanted to be better informed about contraception, but felt judged when using some services, which put them off using them (Young People's Public Health Reference Group 2008; Diva 2010).

The evidence we reviewed showed that many groups of young people were unaware of what sexual health services were available to them (Diva 2010). For example, a consultation with young African asylum seekers and refugees found that, although sexually active, they had little knowledge about local services (Waltham Forest LINK 2010). Their circumstances required a targeted response: service information available in the relevant community languages; specialist services to respond to cultural practices such as Female Genital Mutilation; and, outreach work carried out by women with other young women in the community.

The inadequacy of sex education and advice reported in the consultations is reflected in key statistics on sexual health. Young people (aged 16-24) are still the group most likely to be diagnosed with a sexually transmitted infection (Brooks, Magnusson et al. 2011), and while under-18 conception rates in the UK have been steadily decreasing since late 1990s, they do remain among the highest in Europe (Berthoud, Ermisch et al. 2004; Harris 2010; Brooks, Magnusson et al. 2011).

4.3 The experiences of vulnerable groups

While there are similarities with the views and experiences of children and young people more generally, evidence was found indicating that some vulnerable groups face particular challenges when trying to be healthy.

Although **children and young people with a disability, learning difficulties and long-term health conditions** raised many of the same public health issues as their peers, they also emphasised specific areas of concern, including:

- personal cleanliness and comfort
- being a healthy weight
- having enough exercise
- social contact.

They also had lots of questions about sex education and sexual health they felt unable to ask about at home or elsewhere. They were acutely aware that many of the professionals who worked with them were uncomfortable talking about sex, relationships and sexual health – but they felt they had a need for and right to this information. For some of these young people, managing pain was the most important outcome for being healthy. Without a proper plan in place to treat or help with pain management, other outcomes such as physical health and comfort or emotional well-being could not be achieved (Beresford, Rabiee et al. 2007; West Bromwich 2011).

In a study of **children in care**, 12-21 year olds complained about the lack of information they received around health issues such as sexual health, sexually transmitted infections, contraception and pregnancy, alcohol, drugs, and healthy eating. However, they admitted that they did not listen to what their carers said about any of these issues because they were not their parents (Cafcass 2008). This raises the question of where children in care would seek this information, and whose advice they would listen to and trust. The report indicated that carers were not performing the crucial role of information providers on key health issues that parents typically play, leading to the recommendation that carers need improved awareness and training on health issues.

Young people living in secure establishments have little choice about what they eat and what they do with their time. One qualitative study explored what young people thought helped or prevented them from being healthy in secure care (Morgan 2009):

- They had regular health checks and nursing care, but felt that mental health issues, such as high levels of stress, were not so well addressed

- A good diet and exercise were important, but exercise opportunities were limited, as was their choice of food
- Overeating was a problem for some because of the lack of activities available.

A different view was presented in a consultation with young people in custody, which found that being in there could give them an opportunity to improve their health, that is eat more healthily, exercise, stop drinking and taking drugs. Helping them develop a healthier lifestyle, however, would require custodial establishments to provide fresh and healthy food, regular opportunities to exercise, plenty of time outside, help with alcohol and drug problems, and help to stop smoking (NCB 2007).

Finally, a local consultation with two groups of **Irish Traveller children** raised an alternative list of public health issues that concerned them: air and noise pollution because their sites were located near busy roadways, and a fear that those who went to school would be more susceptible to getting involved in alcohol and drug use (London Network for Nurses and Midwives 2007).

4.4 How public health services could be improved

The consultations we reviewed showed that children and young people are full of ideas about how public health services could be improved, and enthusiastic about taking part in some of these improvements. Common areas that span the research and consultation materials are outlined below.

Health education

- Make public health lessons in school more creative and interactive (NCB 2011b)
- Increase the role and improve the quality of educational programmes including Personal, Social, Health and Economic (PSHE) education (ChaMPs 2011; NCB 2011b).

Information and advice

- Commission child friendly information about a range of public health issues and services (NCB 2011b); this information needs to take into account the needs and views on vulnerable groups (Davey 2008; Norfolk YOT 2009; West Bromwich 2011; NCB 2011a)
- Involve children and young people in the design of public health campaigns (NCB 2011b)
- Recognise that children and young people are themselves a diverse group, who need different kinds of information delivered in a variety of ways

(NCB 2010b; Afiya Trust 2011; National Advisory Council 2011; NCB 2011b)
- Commission young people to create a local directory of child friendly healthy living services and activities to be used by public health professionals (NCB 2011b)
- Develop, in collaboration with children and young people, better strategies for using social networking and other web-based sites (West Bromwich 2011; NCB 2011a)
- Use children and young people's experiences and stories to highlight their public health needs (NCB 2011a)
- Encourage healthy behaviours in schools (NCB 2008)
- Make more information and education on sexual health freely available through schools and health services (Cafcass 2008; Davey 2008).

Services

- Maximise opportunities to stay fit and healthy, for example, through subsidised access to gyms, and a range of hot, cheap, healthy food to be available in schools (Davey 2008; NCB 2008)
- Introduce 'cook and eat' sessions to increase children and young people's confidence in trying new and different foods (Pearce, Kirk et al. 2009)
- Provide better access to specialised staff within schools and colleges who can offer one-to-one guidance on well-being and increase awareness of the choices available to young people (NCB 2008).

Training

Provide more training for health professionals about working with children and young people so they can learn (Davey 2008; NCB 2008; NCB 2010a):

- How to build a good relationship based on trust
- How to treat children and young people as equal and with respect
- To be non-judgmental and a good listener, who is relaxed, friendly and young people-oriented.

4.5 Summary

Children and young people acknowledge the importance of being healthy and having a healthy lifestyle, but do not always feel they have access to the information and advice that would enable them to make healthier choices. They realise that advertising campaigns and peer pressure can make it difficult for some to make that healthy choice, and that those who live in more deprived areas are at greater risk from those kinds of pressure.

Children and young people believe that many public health campaigns are too obviously designed by and for adults, and fail to answer the questions they have about sensitive issues, such as sexual health.

Children and young people want to be involved in public health discussions; in the design, development and evaluation of child friendly campaigns and information; and, the design, development and evaluation of local health services for children and young people. This may be happening, and we received a number of examples of these, but on the whole children and young people's contribution remains unrecorded and therefore impossible to measure.

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5. Shaping national policy and local services

This chapter explores different levels of children and young people's involvement in health consultations or research, and any evidence that their involvement led to service change.

5.1 Children and young people's involvement in health policy

As noted in Chapter 2, although the views of under-16s are largely absent from national health surveys (Hargreaves and Viner 2011), there are a growing number of consultations with children and young people aiming to comment on and influence health policy.

For example, over the past two years, the Voluntary Sector Support project run by the National Children's Bureau (NCB)[8] held a series of consultation meetings with children and young people about recent health reforms, including the 2010 NHS white paper, the 2009 NHS Constitution and the 2010 public health white paper (NCB 2010b; NCB 2011a). Key aims of these consultations were to:

- Raise awareness of the policy areas with young people
- Ask children and young people to help identify the best strategies to share and promote them with other young people
- Enable them to contribute to the development of national policy.

The children and young people welcomed civil servants to their meetings, and felt that their presence made the consultation process more meaningful. Face-to-face contact with officials and health professionals involved in the reforms was seen as evidence that their views were being taken seriously.

In each case, until the consultation event took place, the children and young people involved had been unaware of the consultation papers and presumably most of the reform programme. However, once they were made aware of the proposals, they were keen to know more. They wanted to have a voice in the NHS and public health developments and greater involvement in change at all levels, introducing **an alternative set of priorities** and **recommendations for public awareness campaigns** that they felt better reflected the needs and interests of their age group.

[8] The Voluntary Sector Support project is part of the Department of Health Strategic Partnership Programme.

For example, in the case of the NHS white paper *Equity and Excellence: Liberating the NHS*, their outcome domains differed significantly from those presented by Government, which exemplified 'a health service designed by older people for older people'[9]. The priorities identified by the young people included: better treatments and care at home; clean wards; promoting the diversity of young people and their families; and better emergency care (NCB 2010c).

In the consultation on the public health white paper (NCB 2011b), the young people wanted to add outcomes which they felt were missing from the list presented to them. These included:

- ensuring that everyone is able to live in a healthy, clean environment
- making sure that everything works together to make the NHS more efficient
- increasing the accessibility of services for everyone
- providing better health education.

They suggested **more effective ways of promoting the NHS white paper to children and young people** including: targeting information at schools, developing a simple animated film to describe the changes, and making better use of social media and online fora (NCB 2010a). They wanted to see an easy-read version of the public health white paper promoted directly to children and young people and, having spent part of their consultation day developing their own more age-appropriate campaigns on alcohol, smoking, exercise and diet, hoped these could inform the work of Public Health England (NCB 2011b).

We identified other examples of work undertaken to influence policy and ensure that children and young people's views are heard at a national level. For example, a national consultation with children and young people aged 11-18 commissioned by the Department of Health to look at **the role of the school nurse** (British Youth Council 2011). Key themes that emerged from the consultation were:

- School nurses needed to be more visible to young people, accessible and confidential
- They should be able to offer advice on drugs, contraception, sexually transmitted infections, how to stop smoking, and how and where to access other health services such as counselling

[9] The original domains were: 1. Preventing people from dying prematurely; 2. Enhancing the quality of life for people with long-term conditions; 3. Helping people to recover from episodes of ill health or following injury; 4. Ensuring people have a positive experience of care; 5. Treating and caring for people in a safe environment and protecting them from avoidable harm.

- They should be inviting young people's views about the service they have received.

Having a greater involvement in policy development requires **sustained engagement with groups of children and young people** which continues to involve them in the consultation process. In addition to one-off consultations, young people have suggested ways in which they could maintain their input, as illustrated in Box 5.1.

5.1 Ways to involve children and young people

- Involve them in the design of public health campaigns aimed at children and young people.
- Involve children and young people in monitoring health services at all levels.
- Appoint young people to lead teams of mystery shoppers to scrutinise health services.
- Set up a National Health Parliament for all stakeholders including children and young people, which would debate health decisions, strategy and policy development.

(NCB 2010a)

A guide for commissioners of health services developed in collaboration with children and young people highlights similar features to ensure successful participation, as indicated in Box 5.2.

5.2 Action points for successful participation

- Making participation into a process not a one-off event
- Embedding participation into the commissioning process and ensuring it is supported by the principles and ethos of the organisation
- Preparing support staff and young people to ensure that they get the most out of the work
- Evaluating to ensure e are getting it right and it is making a difference
- Making use of those with expertise and knowledge of participation
- Being flexible and clear about the aims of the participation and what is expected from children and young people
- Using incentives to encourage children and young people to be involved and celebrating the successes of all those involved.

(NHS North West 2011) p. 11

Building on meetings that had taken place over the previous year, Young Minds' National Advisory Council held a stakeholder event which looked at aspects of the NHS 2010 white paper and **the Government's mental health strategy in relation to CAMHS** (National Advisory Council 2010). In addition to the findings discussed in Chapter 3, the young people had strong views about the importance of participation, that is:

- Service user involvement and active feedback should be sought and acted upon
- Participation should be seen as a fundamental aspect of service evaluation and service improvement
- Progress should be fed back to the young people.

Another example we identified was *Making it Better,* a very extensive consultation carried out to strengthen public and patient engagement in health services in Greater Manchester, East Cheshire, High Peak and Rossendale. This was a very large and complex exercise involving 22,000 children, young people, parents, carers and staff, and the findings are too detailed to present here. However, the consultation provides an exemplar of how children and young people can be involved in a health consultation in many different ways (e.g. through interviews, drawings, drama, interactive play, workshops), in a range of settings (e.g. schools, youth groups, Sure Start projects) using the expertise of those who work with children and young people locally (Great Manchester East Cheshire High Peak and Rossendale health care services 2007).

5.2 How involvement can lead to change

Several research studies considered for this review (Coad, Flay et al. 2008; Moules 2009; Hopwood and Tallett 2011; Martin, Hart et al. 2011) promoted the principles of involving children and young people in the methodology used by the researcher, but provided very little information on what happened next – were improvements made to the service, did more of them use the service following any changes made, and did the children and young people involved in the consultation get any feedback? While some consultations reviewed provided examples of changes made, many research and consultation papers did not, raising again the question of **how children and young people are to know if their input made any difference**.

Those who commission or undertake research with children and young people should make greater efforts to provide their findings to the children and young people who took part, and explain to them how and to whom the material has been disseminated. Once they have some idea of how the research or consultation have been used and whether they have influenced policy or led to changes in service provision, they should communicate this to those who took

part in the research through follow-up articles or direct feedback to the children and young people.

In the rest of this section we provide some examples of changes made following consultations (and in a few cases research) with children and young people. Some changes were small and very localised, others more strategic and on-going, but each a result of the involvement of children and young people.

- Young people in Hastings were consulted about a local problem with underage drinking. Their views were used to **create an educational video** which is being shown to all year 9 and 10 students in schools in Hastings (Williams 2011).
- In a consultation with children and young people undertaken on behalf of the Patient Advice Liaison Service (PALS), children and young people were involved in a range of activities including: helping to design a job description for a Young Person's Involvement Worker and take part in the interview panel; developing a lesson plan for a Year 9 PSHE lesson on PALS; and the creation of a diary for children in hospital (NCB 2009). Those involved in the recruitment of the Young Person's Involvement Worker reported that they **learned new skills and increased their self-esteem,** and that the involvement worker appointed met their specifications. The Service planned to **use patient feedback from the diaries to do audits and influence service development**.
- PALS (NCB 2009) also held a series of meetings with young people from a **Young Offender Institution (YOI),** enabling service representatives to address the immediate health needs of individuals (e.g. facilitating access to a dentist), as well as gain a better knowledge of the health needs of this group.
- A survey of young inpatients (Hopwood and Tallett 2011) was used by Sheffield Children's Hospital to develop an **action plan** to address concerns raised by the children and young people involved. For example, in response to children and young people saying there were not enough age-relevant activities to do when they were waiting to be seen, the hospital introduced games consoles and a youth worker to entertain patients while they waited, as well as a bleep system that allowed them to move around the hospital and be notified when their appointment was imminent.
- In Cheshire and Merseyside, a group of **Young Ministers for Health** were consulted about improvements that could be made to school health services, leading to a series of recommendations for change. The role of the school nurse was to be made more explicit to children and young people and times during which they could be accessed by them protected; sexual health services were to become available on site; and the school

health service would establish a formal consultation route for any service redesign to involve children and young people (Cheshire & Merseyside Child Health Development Programme 2009). Because the group continues to meet and take part in consultations, it can comment on whether or not the recommended changes have been made.

- NHS North West commissioned a series of online consultations with children aged 11-18 and their parents to inform its regional Child and Maternal Health strategy (NHS North West 2010). The participants were asked to identify their perceived health risks and concerns, their experiences of local health services, and sources of advice and support. These findings were augmented by additional consultations with existing groups including local youth councils and young ministers for health. The **region's new guide for commissioners of children's, young people's and maternal health services is based on the results of those consultations,** the online surveys and national policy documentation (NHS North West 2011).
- In response to recommendations made in a Care Quality Commission inspection report, Western Cheshire NHS consulted with the **Children in Care Council** to ask them about their health priorities, health assessments, and to help them develop a guide to health services (Western Cheshire NHS 2011). In its report on the consultation, the Primary Care Trust (PCT) included **a response to each of the areas discussed**. It would consider how to include children and young people's health priorities in its Children in Care strategy and action plan; take action to improve health assessments as recommended by the children and ask them for feedback; and would redesign, reformat and make its health services guide shorter.

5.3 Views of being involved in service development

One research paper reports on an evaluation workshop with a local Youth Council which had been set up under the Patient and Public Involvement programme with the express aim of influencing the NHS trust and local health services (Coad, Flay et al. 2008). Although its findings are hardly startling, they illustrate what a group of young people felt after having been involved in a series of consultations over a period of time.

Evidence that their involvement had improved trust services included:

- The young people quoted feedback they had received from hospital staff as evidence of their involvement

- They had gained confidence and felt respected as young people in decision-making.

Although the young people felt their views were taken into consideration, they were still concerned about not being taken seriously. When their views were rejected, they appreciated it when the Director of Children's Services and the Chief Executive of the Trust came to talk to them to explain why a different decision had been made (e.g. based on funding constraints), and to explain the complex reality of the way in which services are organised. On the other hand, when there was no feedback on some of their other suggestions, they felt frustrated.

Suggestions for promoting young people's involvement in health services included:

- Change from a service-focused to a person-centred model
- Make sure there are clear aims and objectives for the group
- Ensure there is an adult gatekeeper to provide support to the group
- The amount of time required should not be too onerous.

5.4 Summary

Children and young people believe they should have a say in decisions about their health and be allowed to take a lead where they are capable. They value the support and advice of their parents/carers, but have their own opinions and want to be able to exercise their own choices. Most of all, they want to be listened and to and have their recommendations acted on; to be informed when they are, or, if they are not, have the decision-makers meet with them to explain why.

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6. Conclusion

At the time when the Government is taking forward a major programme of reform of the NHS and public health service, this review has provided extensive evidence on children and young people's views and experiences of health provision, and how health services can be improved to better meet their needs.

The evidence reviewed has highlighted important learning that national policy makers, local planners and commissioners can use to ensure that children and young people receive a higher priority in the NHS. This learning is summarised in the first part of the chapter.

The review has also identified some large evidence gaps in relation to children and young people's views and experiences of health services, as well as their desire to play a more active role in shaping the NHS. These issues are explored in the second part of the chapter.

We conclude by highlighting some key policy messages emerging from the evidence.

6.1 Making the NHS more child friendly: learning from existing evidence

While the few national health surveys that have monitored children and young people's views and experiences of health provision found high levels of satisfaction, they also found that they rated their experience less positively than older NHS users. Furthermore many research studies and consultations, across physical, mental and public health and including a wide range of groups, show some consistent messages about the way health services need to change to meet children and young people's needs. These include:

- **Parents** are especially important for younger children as 'information providers', both in relation to accessing health support, but also 'translating' information from health professionals and making it accessible for them. However, children and young people also want to be able to receive information directly from health staff.
- This **information** should be **child friendly** and suitable for different age groups. It should explain what health services are available and how they can be accessed, and what children and young people can expect from a service when they use it. Access to good information is important in relation to all health services, but it is particularly important in relation to mental health and sexual health services, as children and young people

are particularly reluctant to seek information, advice and help on mental and sexual health issues.

- Communication from health staff should be underpinned by **respect** and recognition of children and young people's right to be **involved in decisions about their health and care**. As well as learning to communicate with children and young people in general, health staff need learn how to communicate with children and young people with specific communication needs.
- A **good relationship with health professionals based on trust and mutual respect** matters a lot to all children and young people, and is especially important for those receiving long term healthcare and seeking support with mental health issues.
- Children and young people want to access health services in **child friendly environments**, which can cater for their diverse needs. Those with long term care needs have a strong preference for being cared for at home, as far as it is possible.
- Children and young people, like other NHS users, want **services to be effective, flexible and personalised**.
- The **transition from children to adult services** is critical for those who need long term healthcare, including those with mental health problems. The transition **needs to be more carefully managed and planned** in collaboration with young people and their families.
- Responsibility for informing and supporting children and young people with health issues needs to go beyond health professionals. This is particularly the case for children and young people who lack parental support (e.g. in care). **Other professionals**, such as social workers, must be able to advise these children and young people about addressing their health needs and accessing health services.

6.2 Making the NHS more child friendly: filling the evidence gaps

The review has shown that children and young people are very interested in their health and health issues; they have views and can make a constructive contribution to how to improve provision. There is also some evidence of positive health outcomes when children and young people are listened to and play an active role in the management of their health and their care. However, the review has shown some major gaps in the evidence on children and young people's views and experiences of health provision.

Successful health planning relies on the regular gathering of robust research evidence to monitor satisfaction with and the effectiveness of health services, and to identify how these may need to change and improve. We have seen that under 16 year olds are largely excluded from NHS surveys. This represents a large evidence gap that should be filled by **ensuring that NHS surveys are based on samples and child friendly methodology that adequately represent all NHS users,** including those under the age of 16.

The review has highlighted a number of examples of consultations with children and young people about health issues, both at the national and local level. However, we do not know to what extent these consultations represent rare examples of good practice or are now becoming common practice in the NHS and public health, nationally and locally. Moreover, we do not know whether the consultations make any difference, and whether children and young people involved were told if and what difference their input had. **Robust and regular research evidence** is needed to establish to what extent **children and young people are consulted over a range of health issues and are able to see how their input is used to reform and improve the NHS**. Regular gathering of this evidence using a robust tool can underpin a commitment to measuring the progress made from the perspectives of these important users.

6.3 Making the NHS more child friendly: key policy messages

Evidence for the review highlight some key messages for policy makers. Children and young people want a say in decisions about their health and have strong views about what good health services for them and their peers should look like. **Mechanisms to hear the voices of children and young people should be embedded at every level** of the system:

- In the work of local and national HealthWatch
- As part of Health and Well-being Board's assessment of local needs and development of a local health and well-being strategy
- In the commissioning decisions of GP-led clinical commissioning groups and Directors of Public Health and the NHS Commissioning Board
- In the work of Public Health England, including the development of health promotion campaigns and advice to Directors of Public Health
- In the day-to-day decisions of practitioners.

Alongside the direct involvement of children and young people themselves, Directors of Children's Services, lead council members for children and young people and wider **children's service leaders** (e.g. head teachers) should be **champions for children's health in local strategic partnerships**.

Health Education England should ensure that **health practitioners are confident in communicating effectively with children and young people**, ensuring children and young people are well informed about their health and their options and empowered to make choices about their care. This should include involving children and young people in the training of health practitioners.

Clinical commissioning groups must develop an excellent understanding of what a child-friendly service and setting looks like, incorporating the *You're Welcome* standards (Department of Health 2011) into commissioning decisions and contracts.

Children and young people should be **included in all relevant NHS patient surveys**, and their experiences of services should be reflected in the NHS and public health outcomes frameworks.

As we move into the implementation of the reforms, government must ensure that the fragmented commissioning of services for children and young people does not make it even harder for them and their families to receive **seamless support**. This particularly an issue affecting children and young people with complex or long term needs and those moving from children to adult services.

6.4 Final thought

This review has highlighted important learning for national policy makers, local planners and commissioners. Acting on the recommendations from this learning, nationally and locally, would reflect a commitment to giving children and young people higher priority in the NHS.

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Appendix A Respondents to the call for evidence

Organisations

Action for Sick Children

Asthma UK

BLISS

Bridgewater Community Healthcare NHS Trust, Halton and St Helen's Division

CAMHS Leicester, Leicestershire and Rutland

Canterbury City Council Children and Youth Team

Central Essex Community Services Safeguarding Team

Central London Community Healthcare (CLCH), hosted by NHS Kensington and Chelsea

Central Manchester University Hospitals NHS Foundation Trust

Changing Our Lives

Children and Young People HIV Network, NCB

Children's Rights Alliance for England (CRAE)

chYps, EllenorLions Hospices

CLIC Sargent

Contact a Family

Council for Disabled Children

Deputy Director - Service Experience Directorate, NHS North of England

Dorset Children's Trust

Dorset Healthcare NHS University Foundation Trust CAMHS Team

Epilepsy Action

Food Standards Agency

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Guy's and St Thomas' NHS Foundation Trust

Lancashire Care NHS Foundation Trust

London Network for Nurses and Midwives (Children and Young People's Group)

MEND (Mind, Exercise, Nutrition...Do it!)

National Deaf Children's Society

NCB

NHS East Midlands

NHS Hillingdon Primary Care Trust

NHS Institute for Innovation & Improvement

NHS Leeds

NHS North of England, Service Experience Directorate

NHS North West

NHS Nottinghamshire County

NHS Sheffield

NHS Western Cheshire and NHS Wirral

Norfolk County Council

Nottinghamshire County Council (Children, Families and Cultural Services)

Office of the Children's Commissioner

Oxfordshire County Council

Picker Institute Europe

Play Therapy UK

Poole Hospital NHS Trust

Royal College of Nursing

Salford Royal NHS Foundation Trust (Speech and Language Therapy Services)

School Food Trust

Sheffield City Council

Sheffield Health and Social Care NHS Trust

Sheffield Teaching Hospitals NHS Foundation Trust

Southend Borough Council

Sussex Community NHS Trust

Teenage Cancer Trust

The Children's Society

The Communication Trust

The Foundation for People with Learning Disabilities

Together for Short Lives

University College Hospital (NCRI Teenagers and Young Adult Clinical Studies Group)

University Hospitals Bristol NHS Foundation Trust

University of the West of England

Voluntary Action Waltham Forest

Whittington Health (Women, Children & Families Division), Haringey Sexual Health & Contraceptive Service

Young Children's Voices Network, NCB

YoungMinds

Youth Justice Board

Individual contributors

Susie Aldiss, London South Bank University

Dr Janice Allister, Royal College of General Practitioners (RCGP) Clinical Champion for Child Health

Mary Brady, Kingston University and St George's, University of London

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Val Bayliss-Brideaux, Communications and Engagement Manager, NHS Manchester

Dr Harriet Conniff, Clinical Psychologist, Norfolk & Norwich University Hospital

Dr Ffion Davies, Royal College of Paediatrics and Child Health

Dr Ana Draper, Macmillan Consultant Systemic Psychotherapist

Anna Gill, Parent Representative, Children & Young People's Health Outcomes Forum

Professor E. Alan Glasper, University of Southampton

Dr Kathryn Greenwood, University of Sussex

Jean Gross, Government Communication Champion for children and young people with speech, language and communication needs

Dr Lesley Hewson, Child and Adolescent Psychiatrist (retired)

Professor M. Elena Garralda Hualde, Imperial College London

Dr Sarah Kendal, University of Manchester

Dr Susan Kirk, University of Manchester

Dr Joan Livesley, University of Salford

Dr Janet McDonagh, University of Birmingham & Birmingham Children's Hospital NHS Foundation Trust

Dr Jo Potier, Clinical Psychologist, Liverpool 16-18 Team

Dr Duncan Randall, University of Birmingham

Vicky Roe, Selective Mutism Information and Research Association

Dr Sharon Taylor, Imperial College London

Trudy Ward, Interim Head of Community Children's Nursing, Sussex Community NHS Trust

Patrick Welsh, Durham University, Wolfson Research Institute

Dr Anne Worrall-Davies, Consultant Child & Adolescent Psychiatrist

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Appendix B Details of search strategy

The table summarises the database searches.

Database	No of results	No selected
NCB ChildData	460	64
Applied Social Sciences Index and Abstracts (ASSIA)	44	8
British Nursing Index	52	5
Social Care Online	13	4
Medline	32	9
PsycInfo	47	1
Sociological Abstract	29	1

There was a further screen, at the summary stage, of the 92 publications selected with a final total 66 being considered suitable for the review.

The keywords used in the searches were:

- Children or adolescents(su) and consumer satisfaction(su) and date >2006
- Adolescents(su) and views or participation(ab) and date >2006
- Young people's views/adolescents views and dt >2006
- Adolescents(su) and health(su) and views or participation(ab) and date >2006
- Children and health or health services and views and dt >2006
- Children's views and dt >2006
- Young people's views and health/health services/mental health services and date >2006.

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