

## Chapter 4

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# The voices of children and young people

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*'We're the next generation: if we're supported to do well and we become healthy adults physically and emotionally, we can do good and look after the future generations.'* – 19-year-old female from the YoungMinds focus group

### Overview

The aim of this chapter is to gather the voices of children and young people and to incorporate their views into the recommendations for this report. We start by understanding why the opinions of children and young people are so important to include in the development and implementation of health and social care policy. After a discussion of the methods used to gather their voices, we explore what children and young people have said about health, healthcare and wellbeing, including their views on specific themes that have arisen in other chapters of this report. We then examine particular areas of concern voiced by the four populations of children that this report focuses on: children with neurodisability, mental health problems, looked-after children, and those within the youth justice system. We also consider the views of representative parents. All the evidence from this chapter is ultimately brought together in the conclusion to produce a Children and Young People's Manifesto for Health and Wellbeing; and by doing so, we propose the children and young people's recommendations for this report.

### The participation of children and young people in health policy

Patients working in partnership with clinicians and carers in decisions about their healthcare is one of the guiding principles set out in the NHS Constitution<sup>1</sup> (see Box 4.1). There is also an expectation that patients, service users and the public participate nationally and locally in the development, implementation and accountability processes of health and social care policy and services. The Health and Social Care Act 2012<sup>2</sup> set duties for the NHS Commissioning Board, clinical commissioning groups, Monitor, and health and wellbeing boards with regard to involvement of patients, carers and the public. Commissioning groups have to consult the public on their annual commissioning plans and involve them in changes that affect patient services. The Act also established Healthwatch England as a national body representing the views of users of health and social care services, other members of the public and local Healthwatch organisations. It advises and provides information to the Secretary of State, NHS England, Monitor, English local authorities and the Care Quality Commission on the views of users of health and social care services and their experience of such services. In addition, local Healthwatch organisations, based in and funded by local authorities, help to ensure that the views and feedback from

patients and carers are an integral part of local commissioning across health and social care.

#### Box 4.1 The NHS Constitution for England, 26 March 2013

The NHS aspires to put patients at the heart of everything it does. It should support individuals to promote and manage their own health. NHS services must reflect, and should be co-ordinated around and tailored to, the needs and preferences of patients, their families and their carers. Patients, with their families and carers, where appropriate, will be involved in and consulted on all decisions about their care and treatment. The NHS will actively encourage feedback from the public, patients and staff, welcome it and use it to improve its services.

This expectation for patient and public participation has no age limit. Children and young people (CYP), so far as they are able (and when appropriate with the support of their parents or carers), should be encouraged and facilitated to participate in decisions about their own care and, more broadly, about the health and social care services and policies that affect them. This principle is set out in the United Nations Convention on the Rights of the Child (1989)<sup>3</sup> and the Children Acts of 1989 and 2004,<sup>4,5</sup> and has been policy for successive governments,<sup>6–8</sup> including in response to the Children and Young People's Health Outcomes Forum recommendations, *Improving Children and Young People's Health Outcomes: a system wide response*.<sup>9</sup>

The practice of engaging with children and young people on health policy has developed a great deal over the last 15 years,<sup>10–14</sup> with more investment in resources and new dedicated staff employed in many organisations for this purpose.<sup>14</sup> There is ample evidence that demonstrates that young people value their role in participation<sup>12,13,15–21</sup> and the clear benefits that can be realised through consulting with them.<sup>10,22</sup> In 2005, the National Institute for Health Research created the Medicines for Children Research Network to speed up the process of studies for medicines for children and young people. More recently, organisations across the new health and care system are developing their processes to increase the role of young people in decision making. The Care Quality Commission is involving children and young people in their inspection activities, and Healthwatch England has appointed a children's advocate to its board. Local Healthwatch bodies are being supported by the National Children's Bureau to include children and young people.<sup>23</sup> In line with these changes, NHS England is introducing three new initiatives involving children and young people. Firstly, the expansion of the Friends and Family Test will be rolled out for children's services to all areas by March 2015 so that children and young people can participate in giving their views as part of normal patient feedback processes. Secondly, a strategic voice for children will be formalised through an NHS youth forum, to be established with the British Youth Council, that will hold NHS England to account. Finally, in

2014, new children's experience measures will be developed for the NHS.

There is, however, still a long way to go; as the Children's Commissioner recently highlighted, 'children's participation has not been sufficiently embedded into everyday practice and largely relies on the commitment of key individuals'.<sup>13</sup> Young people participating in focus groups commissioned specifically for this report echoed these views. One young person said:

*'More of an active step is needed to take on board the views of children and young people; there are lots of focus groups but these are often targeted at parents, and young people will have very meaningful things to contribute. It would be good to have more opportunity for participation across more NHS services.'*

Crucially, patient feedback surveys, as a mechanism for children's participation, are nearly non-existent. A review of national surveys undertaken between 2001 and 2011 showed that fewer than 3% included the views of under-16s.<sup>24</sup> Although this issue is being partially addressed by some of the initiatives from NHS England, further steps should be taken to include the voices of children and young people in all relevant NHS surveys as recommended by the Children and Young People's Health Outcomes Forum in 2012.<sup>25</sup> Steps are also needed to involve groups that are often excluded from participation, such as very young children, asylum seekers and the groups highlighted in Chapters 9–12.<sup>11,12,26–31</sup> The views of children and young people are particularly under-represented in areas such as health treatment services,<sup>28</sup> developing ideas, setting the agenda, commissioning, delivery and evaluation,<sup>13</sup> so that children and young people are mainly involved in the tokenistic 'sounding out' of ideas. There is also a need for more evaluation and more rigorous evidence of outcomes<sup>27,29,32</sup> to demonstrate whether or not the feedback from young people is acted on and the quality of the decisions made in response to their views.<sup>10,28,33</sup>

There is, however, a mood for a change. At a recent conference attended by more than 100 young people and health workers, 'Embedding Children and Young People's Participation in Health and Social Care Services', one of the speakers highlighted that 'we're at the tipping point of engaging children and young people in health and social care'. Part of this process of engagement is 'closing the loop of recommendations'; we need to get better at listening to young people's recommendations and then feeding back to them the changes that have been made as a result of their suggestions. If 'our children deserve better', we therefore need to hear what they have to say and then act on it. That is what we have aimed to do here; this chapter is a celebration of the voices and recommendations of children and young people, which concludes with their Manifesto for Health and Wellbeing.

## Methods

### Literature review

A literature review was carried out using a search of electronic databases, including Social Policy and Practice, Embase and Web of Science.

The terms for the search were:

- those relating to young people and their views (young people\* or young person\* or teenage\* or teen or adolescent\* or child\* or youth\*) adjacent by three words to (represent\* or voice\* or participa\* or opinion\* or feedback\* or view\* or perspective\* or satisfac\*) **and**
- those relating to health (welfare\* or NHS\* or hospital\* or doctor\* or nurse\*) **and**
- those relating to the types of young person participation (focus group\* or webinar\* or workshop\* or interview\* or review\* or survey\*) **and**
- those relating to England (England\* or English\* or NHS\* or United Kingdom\* or UK\* or brit\*).

Criteria for inclusion were sources written in English since 2004<sup>12</sup> and only relating to the UK, principally England. These yielded 206 results in Social Policy and Practice, 657 results in Embase and 342 results in Web of Science on 16 July 2013. Conference abstracts were discarded.

Other material was identified through the references of relevant papers and following recommendations from key individuals. The websites of significant bodies such as the National Children's Bureau, YoungMinds and the Children's Commissioner were also searched for relevant material. We achieved saturation of topics, suggesting that our research had been sufficient.

### Participation of young people

Four focus groups/workshops were commissioned specifically for this report. The young people were chosen to be representative of wider groups of views and we used these groups to triangulate issues from the literature review. Two focus groups included children aged between 13 and 22 affiliated with the Royal College of Paediatrics and Child Health's (RCPCH's) Youth Advisory Panel; there were five children in one focus group and eight in the other, with some overlap of attendees. The third focus group involved seven young people aged between 17 and 23 affiliated with YoungMinds. Many of those from YoungMinds suffer from mental health problems, and some are involved with the looked-after care system. During these three focus groups the young people were given the opportunity to reflect on an early draft of this annual report and highlight key areas that they wanted the Chief Medical Officer to address. Quotes from these focus groups are included throughout this chapter. The fourth workshop involved eight young children aged between 5 and 13 from Kids Company. They took part in a workshop on the theme of 'Healthy living', during which they

produced some of the artwork for this report and discussed their views of health, health services and being healthy. Some of the quotes from the Kids Company workshop are included throughout this report.

## The voices of parents

We also consulted five parents, including parents of children with neurodisability, mental health problems and chronic conditions. These telephone interviews were conducted during August and September 2013, using an interview guide. Most of the parents we spoke to are involved with patient groups and act as parent representatives for a number of organisations. As with the young people, the parents were chosen to be representative of a wider group of views and we used the interviews to triangulate issues from the literature review. Parents were recruited through the Children and Young People's Health Outcomes Forum or through introduction via parents who had been interviewed. As with the young people's focus groups, parents were given the opportunity to reflect on an early draft of this annual report and highlight key areas that they wanted the Chief Medical Officer to address. Quotes from these interviews are also included throughout this chapter.

## What children and young people say – findings from the literature review and focus groups

In this section we explore five key areas identified as being important for children and young people (CYP) for health and wellbeing. They are:

- being informed and having a say in decisions about their care
- child-friendly, personalised care
- access to age-appropriate services as they grow, and support through the transition to adult services
- understanding their rights and responsibilities
- the role of school.

*'I don't know if it exists but something as simple as an online list of all the services that can be accessed in your area would help.'* – Young person from an RCPCH focus group

### Being informed and having a say in decisions about their care

Two of the main themes highlighted in the literature and our focus groups were that **young people receive insufficient information about their health and health services, and they want more say in decisions about their own care.** In particular:

- **Where to go** – CYP want better information about where to go locally for help and trustworthy health advice,<sup>20,34–36</sup> including the availability of child-friendly services, the locations and costs involved.<sup>34</sup> They have said that not knowing what services are available can result in their not seeking urgently needed help.<sup>37,38</sup> On some occasions, health professionals were not able to direct them to appropriate child-friendly services and they suggested that to overcome this they could work with professionals to **create a local directory of child-friendly services for users and health workers.**<sup>17</sup> Young people in our focus groups suggested having simple flow charts or information available at GPs and at their schools to show them how to access health services.
- **Information about consultations** – CYP would like more information about symptoms, prognosis, treatment and signposting to sources of further advice.<sup>34</sup> They talked about the **usefulness of a printout or email from the doctor after their appointments with a summary of such information.**<sup>34</sup> They were not always told why they were being referred if a referral was made<sup>11,39</sup> or what would happen at their next appointments,<sup>26</sup> and they wanted this to be addressed.

*'It would be very helpful to know what is going to happen, even when you are going to speak to a GP or counsellor. You wouldn't want to see someone if you didn't know what the outcome would be; the more you know the more comfortable you will feel.'* – Young person from an RCPCH focus group

- **Presentation** – CYP want information to be presented in a clear, concise, accessible and child-friendly way, with pictures and diagrams if applicable.<sup>11,13,21,34,37</sup> Young people in our focus groups and some of the parents we interviewed agreed with the need for appropriate and impactful presentation.

*'Young people are so energised, motivated, full of passion and energy; and we educate them using only dry ways... We need to think creatively about how we communicate with this group – and the best group to show you how to do this are the young people themselves, whether it is memes, social media and whatever gadgets that they are able to get hold of.'* – Parent

A number of channels for delivering health and health service information have been suggested in the literature, including posters, leaflets, television, websites, health apps and social networks that can be accessed easily, confidentially and at no cost, in a number of settings, including schools.<sup>13,17,21,34</sup> **CYP also value hearing and learning from the past experiences of other young people.**<sup>13,34</sup>

The internet is increasingly the preferred source of information for young people. **In a recent study looking at preferences for sources of sex and relationship education (note that answers were not mutually exclusive), 45% of 13-14 year olds said they preferred websites as a source of further information**, about 30% preferred each of magazines, phone lines and school, only about 20% favoured each of drop-in centres or their homes and less than 10% preferred each of youth clubs and leisure centres.<sup>40</sup> Young people were reassured by the NHS logo on apps but were concerned that an SMS message could be spam.<sup>34</sup> In our focus groups young people said that internet sites and social media provide an effective method for reaching young people about health issues and should be better utilised for this purpose.

- **Involvement in their own care – In general, young people were unhappy with their role in making decisions about their own care.**<sup>11,24,26,28,38</sup> **They value being involved in these decisions**<sup>11,20,21,25,41,42</sup> and want to take the lead if appropriate,<sup>25</sup> although they know that is not always possible.<sup>11</sup> For example, **they wanted to give consent for procedures carried out on them.**<sup>12</sup> CYP using specialist health services perceive themselves as experts on their own conditions and health status, and want those with non-specialist knowledge to acknowledge this expertise and specialists to recognise them as partners in their care.<sup>20,38</sup> Benefits of involving young people include empowerment for the young person, helping professionals to fully understand their illness and how it affects them, equipping young people with the skills for making decisions about their health in adulthood,<sup>11</sup> and helping them to 'feel prepared and less anxious about undergoing operations and treatment'.<sup>42</sup> One study highlighted how it can avoid diagnostic delay and poorer psychological outcomes.<sup>43</sup>

The evidence suggests various ways of involving children and young people in their own care,<sup>11,42</sup> which to some extent is affected by the age, maturity and communication skills of the individual.<sup>41</sup> It has been suggested that health workers should alter a child's level of involvement in consultations as he or she matures.<sup>44</sup>

## Child-friendly, personalised care

Young people want child-friendly services, including good interaction with health professionals and easy access to services where they feel welcome and not belittled. Some did not feel that health professionals took them seriously enough.<sup>31,45</sup> They highlighted **the need for good communication by health professionals, particularly listening and treating them with respect.**<sup>26,38,46</sup> They do not like jargon, an inappropriate level of language or explanations that they cannot understand.<sup>11,12,15,28,34,38</sup> They want health workers to be trained to communicate effectively with them,<sup>11,15,25</sup> and to talk directly to them and not just their parents.<sup>11,12,15,28,38</sup>

*'I've experienced this myself: a physician will look at me, and ask me a question about my child, and I ask my child, and she replies and the clinician waits for me to reply, and it is so rude and disrespectful... having the ability to communicate well with children and young people and the intention to do it should be the aim of your care.'* – Parent

**Good relationships with health professionals who are familiar and can be trusted is valued by young people,**<sup>20,35,37</sup> and they particularly appreciated having relationships with people who had known them for a long time and were empathetic to their needs.<sup>13,37</sup> In a 2012 survey of more than 93,000 young people in the UK by the Schools and Students Health Education Unit, up to 23% of the 12–15-year-old females surveyed reported feeling 'quite uneasy' or 'very uneasy' on their last visit to the doctor.<sup>47</sup> The importance of professional expertise and competence was also highlighted,<sup>20,37,48,49</sup> as were accessibility and availability.<sup>37</sup>

Young people have repeatedly commented that they want **improved co-ordination, communication and integration** between health workers so they do not have to keep repeating their experiences to different professionals.<sup>11,20,31,35,38,50–53</sup> They also want improved continuity of care, with one person nominated as their care co-ordinator.<sup>46</sup> Some agreed that **an advocate to help navigate the system and fight on their behalf would be helpful.**<sup>20,54</sup> This was particularly the case for looked-after children, children with neurodisability and those with long-term conditions, who felt that seeing one person helped develop trust, confidence and independence. They were concerned that receiving care from different health professionals who did not know the nuances of their condition or their individual background meant that their progress could not be monitored effectively or encouraged.<sup>31,46</sup>

**Better access to health services for CYP** was thought to be a priority by those taking part in our focus groups. They identified several difficulties with access that can result from the following:

- **Disability** – *'I have a wheelchair, and for those who have a condition like me, getting to places is hard. Some services don't have ambulances or offer transport. Black cabs or buses are not helpful and private taxis are too expensive. Young people should have help to access their services... it can cost £70 for me to get to an appointment.'*
- **Living in remote areas** – *'I live in a rural area in the North of England, in the middle of nowhere. I couldn't access help until I could drive, I couldn't get a bus, and my mental health deteriorated; within two weeks I was sectioned. If I could have got help earlier I would have avoided it.'*

## ■ Not being able to consult medical care

**independently** – *‘There are lots of issues that young people might not want to ask their parents about, and they can’t go to the GP without their parents’ help, either in getting them there during school hours or without a car. They need another route to find the answers they need without needing to utilise their parents.’*

**In general, young people want their services to be easy to access at convenient, non-stigmatising locations, close to home.**<sup>20,52,55</sup> **They want flexible opening times, including weekends, late afternoons and early evenings.**<sup>20,38,56</sup> The need for late afternoon clinics was echoed by young people in our focus groups:

*‘They should have clinics from 5 to 8pm so as not to disrupt school or your working life, especially for those with complex conditions. You can become disadvantaged if you have to keep leaving school; it affects your education and why should it?’ – Young person from an RCPCH focus group*

There was some support for a ‘drop-in centre’ format, especially for sexual health clinics;<sup>20,52</sup> however, some young people reported waiting for long periods at such services, where they were bored, nervous and no one checked on them while they waited.<sup>38</sup>

## **The role of GPs in child-friendly services**

There is evidence that, in general, many young people are not satisfied with GP services and are less satisfied with GP care than adults are.<sup>57</sup> Often they and their families attend Accident & Emergency services unnecessarily as they are unwilling or unable to access their GP.<sup>58</sup> In a recent survey of 11–19 year olds, over a quarter of those taking part said that they were not comfortable visiting their GP, either because they felt embarrassed, felt judged, found it hard to explain their problem or did not understand what the GP was saying to them.<sup>36</sup> In another survey, over a third of young people asked rated their last contact with their GP as being average or poor.<sup>59</sup> In one study, young people diagnosed with cancer reported that the possibility of early diagnosis and their chances of being taken seriously were affected by ‘not having access to a regular GP’.<sup>53</sup>

*‘GP training is geared towards adults, they treat children as small adults and they need more guidance. 15-16 year olds are not children but they are not adults either’. – Young Person from a RCPCH focus group*

A recent report by the National Children’s Bureau<sup>57</sup> examined how general practice is working for CYP and found that poor communication, lack of involvement in making decisions about their own care, the GP waiting room environment,

access to services, and lack of paediatric or specialist training were all problematic issues for CYP and their families. The report made various recommendations that resonate with comments from our focus groups. The young people we talked with also thought that GPs should all have specialist training in paediatrics, including learning how to communicate with different age groups.

Some suggested having specialist paediatric GPs just for children and young people in primary care. They didn’t always like having a family doctor:

The also said that they wanted to be able to access their GP outside of school hours, between 4 and 8pm. They suggested that GPs could work more closely with schools to teach students about health issues and how to navigate the health system. They also wanted GPs to play a greater role during the transition to adult services. The young people suggested that GPs should be more proactive in including them in their decision making for services, and they wanted to have more of a participatory role in the new clinical commissioning groups.

*‘I don’t want the same doctor as my family, where the doctor can tell my parents that they have just seen me about something. I want my own doctor or a separate doctor that is just for children and young people.’ – Young person from an RCPCH focus group*

## **Access to age-appropriate services as they grow, and support through the transition to adult services**

*‘This is hugely important, not just for teenagers, but also for paediatric patients. My daughter’s hospital has created separate waiting areas; for those in secondary school and above, and for those below. The children’s area has toys, and is big enough for them to run about and be sticky. The teens have a games table, and some computer games and posters on subjects that might be beginning to affect them like drinking and driving that you can’t put in the paediatrics area. This works really well for both sides.’ – Parent*

## **One area repeatedly addressed in both the literature and our focus groups was the lack of age-appropriate services, especially for teenagers.**<sup>11,16,20,51</sup>

Young people have said that staff are unable to communicate appropriately with their age group and that they are often placed on paediatric wards, with babies and pictures of ‘giraffes’,<sup>11,15,20,25,46,50</sup> which they view as inappropriate for their needs. Alternatively they are placed on adult wards,<sup>52</sup>

which they find daunting, boring or isolating, where they receive little educational support or information, where too much independence is demanded of them and where they are exposed to inappropriate risks, including serious physical and sexual abuse on adult psychiatric wards.<sup>11,60</sup>

**Research demonstrates that the quality of care and the experience of teenagers are best when they are cared for on wards specifically for their age group.<sup>25,61</sup>**



Source: Kids Company

Children and young people want welcoming, friendly spaces with age-appropriate entertainment such as magazines, games, books and toys on the wards and to keep them occupied while they wait for appointments.<sup>11,26,34,38,46</sup> They also suggested phones and computers to contact family and friends<sup>38</sup> and flexible visiting times for inpatient wards.<sup>15</sup> Play specialists were valued.<sup>11,46</sup> Cleanliness and safety of the environment were seen as a high priority.<sup>15,46,51</sup> They complained about the food quality, lack of choice and the noisiness of wards at night.<sup>38</sup>

**Managing the transition from children's to adult services has also been consistently identified as a problem for young people, in particular for some vulnerable groups such as those with long-term disabilities and mental health problems.<sup>11,16,21,38,45,60,62</sup>**

Young people in our focus groups felt passionately about this issue and wanted a complete overhaul of the transition process across specialties.

Problems highlighted include:

- lack of an integrated structured transition process<sup>11</sup>
- lack of support during transition<sup>11,63</sup>
- lack of clarity about how to navigate adult services, young people describing themselves as lost or in limbo at the time of transition<sup>60</sup>
- difficulty in adjusting to the differences between adult and children's services in a short space of time, such as having to stay in hospital alone and suddenly needing to take on all responsibility of their own care<sup>11</sup>
- health professionals in adult services lacking understanding of being a teenager and being able to communicate effectively with them<sup>62</sup>

- the loss of relationships with trusted professionals and the loss of continuity of support.<sup>11,63</sup>

*'Leaving Child and Adolescent Mental Health Services (CAHMS) felt like I was falling off a cliff; I lost the support and fell through the gaps... Once you are 18 they treat you like you are responsible, but overnight that doesn't change, we still need that support.'* – Young person from YoungMinds focus group

*'Moving from child services to adult services, I have felt the pivotal services I require fall away and am left helpless and almost stranded.'* – Young person from an RCPCH focus group

**Young people have said that these problems can lead to disengagement with the health service, often at a critical time.<sup>38,51,60</sup>** Solutions identified by young people include services developing a more co-ordinated transition process<sup>62</sup> with more information about the process and increased support,<sup>46</sup> and for the process to begin earlier and develop at a slower pace according to individual needs through consultation with them and their families. The need for a slower, more staggered period of transition that starts earlier was also highlighted by some young people in our focus groups who pointed out that 'you don't change overnight'.

Those taking part in our focus groups suggested that there should be national guidelines for transition to ensure consistency across services. They wanted a specific transition care plan with more information, introductions, pre-warning, support and signposting. They also suggested that **at the time of transition there should be joint clinics between paediatric and adult services, where a young person can get used to adult services and key information can be shared so that the experience of transition from one service to another becomes seamless.**

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*'I want my paediatric clinician to introduce me to my adult one and I want the three of us to meet and discuss what's happening next so I feel secure in moving on.'* – Young person from an RCPCH focus group

### **Changing the boundaries of children's services**

One of the discussions arising from this report was the possibility of extending children's services to age 24, in line with the UNICEF definition of a youth. Young people from the focus groups thought that this would be very beneficial so that there was more time to manage transition. Many did not feel ready to enter adult services at age 18.

*'Eighteen is a crucial part of someone's life, you might be leaving for university or going on to employment. You need more support at that time in your life and 18 is not exactly the easiest time, it would be better if you could delay this transition, even if up to 24.'* – Young person from an RCPCH focus group

CYP thought that there could be a specialist service for 16–24 year olds that included transition preparation. Those in the RCPCH focus group wanted healthcare at university to be part of the paediatric healthcare journey.

*'They certainly should not be transitioned to adult care at 15-16 years old, my daughter has diabetes and I am dreading her being in a waiting room with adults who have lost toes, limbs and legs; it is not what they want to see, and it is not appropriate for them to be there with them'* – Parent

## Understanding their rights and responsibilities

**CYP want to know their legal rights and the health policies applicable to them.**<sup>21,50</sup> They want policies to be **presented in child-friendly formats**, possibly using images, film and social media with child-friendly versions of documents.<sup>34</sup> They suggested that health policy could be taught at school or that health organisations could raise awareness and improve understanding about the work they do with <sup>11,13,50</sup>

**Privacy and confidentiality were particularly highlighted as an issue for young people, both in the literature and in our focus groups.**<sup>11,15,20,35,37,46,64–66</sup> In one study, one in four young people asked felt that they were not given enough privacy when being treated or examined.<sup>11,26</sup> Children did not like staff to talk about them and their condition in front of other people on the ward.<sup>38,67</sup> There were concerns about whether their disclosures would be treated confidentially by all staff, including GPs and reception staff, and they wanted information to be shared only on a 'need to know' basis.<sup>20,51</sup> Confidentiality was a particular concern for those living in rural areas,<sup>38</sup> for looked-after children<sup>64</sup> and with regard to mental<sup>38</sup> and sexual health, where in some cases concerns of confidentiality and privacy prevented young people from using services.<sup>38,55,56,68,69</sup> They voiced that they were uncertain about their confidentiality rights,<sup>66</sup> and this was highlighted repeatedly in our focus groups where young people said they wanted a simple explanation of these rights to increase their understanding and therefore their confidence in using health services. Young people in our focus groups were also worried about their families finding out about their confidential information. Our focus groups highlighted that even when young people go to the GP with a family member they might still want to keep

things confidential from them, and they wanted health practitioners to recognise this.

*'We need to know when things are confidential. When you see a doctor who is your entire family's GP you feel insecure and ask 'Will they tell my parents?' You wonder who else will find out.'* – Young person from an RCPCH focus group

*'It should be common practice to ask children if they want to be seen alone without their parents... if it becomes normal policy to ask, it will help a lot. Sexual health clinics do that a lot.'* – Young person from an RCPCH focus group

Parents largely agreed with the need for increased confidentiality and knowledge of confidentiality rights for, some of their children having had experience of poor practice in this area. However, one parent pointed out some of the difficulties from a different perspective:

*'I have a daughter with mental health issues, and I could not get any useful information out of them [health services], as my daughter didn't want me to know anything, but I felt she was not in a mental state to make that decision... I found it hard to know what to do, and as a mum it was pretty awful not to know anything about what was going on.'*

**The right to complain** – CYP have highlighted that they are not sure how and where to register complaints in the NHS. Indeed, a recent report suggests that **access to and use of complaints processes for CYP is under-developed.**<sup>59</sup> Young people say that they are not provided with information about their rights to complain, nor do they know how to do so, and that the system can be so complicated that often they do not bother. Furthermore, they say that when complaints are made through formal channels, often staff are not trained to receive and act on complaints by young people.<sup>59</sup> They want increased awareness of complaint services, which they say should be fully inclusive of their needs, including training staff to relate to them.<sup>70,71</sup>



**'The right...': The Children's Rights Manifesto – what our young people believe are the innate rights of children.** Source: Kids Company

## The role of school

CYP thought that school should play **an important role in health and wellbeing, not only in terms of educating them on health issues**, but also as a setting for health professionals, including school nurses or other services such as sexual health drop-in clinics.<sup>68</sup> The literature review demonstrated that want access to specialised staff in schools for individual guidance and support for wellbeing,<sup>11,72</sup> the type of support depending on the individual. In one evaluation of extended school services, children from black and minority ethnic backgrounds wanted help with health and wellbeing; those from deprived backgrounds wanted support for bullying; and girls were more likely to want support with matters relating to bullying, sexual health and examination stress.<sup>20</sup> CYP also consider school to be **a centre to encourage healthy behaviours, including healthy eating**,<sup>72,73</sup> through, for example, 'cook and eat' sessions to increase their confidence in experimenting with a variety of foods.<sup>11,74</sup>

Young people in our focus groups said that 'schools have a responsibility to teach life skills' as that is where young people spend most of their time, and that school was a good place

to access large numbers of young people who usually do not need to see health professionals and so may miss access to key health messages. They highlighted that some young people, such as looked-after children or those from single-parent families, might not get full parental support at home so school provides 'a chance for health and equality to be levelled out'. They also reflected that school would be a good forum for feedback and participation in decision making on health topics from a range of young people who might not normally get involved in participation activities.

Young people in our focus groups wanted teachers to be more understanding about school absence for health issues. They stressed that they may not want teachers or fellow students to know all the details of an absence, especially if it involved accessing emotional support.

*'If you walk into class half way through the day, the teacher always asks 'Where have you been?' in front of the whole class! So then all the students want to know and it is hard to keep it from them as they pester you to find out why you weren't there; school teachers are no different.'* – Young person from an RCPCCH focus group

**School plays a wider role for children with chronic disease or disability, for example in supporting them through their disease**, which was valued by young people and their families.<sup>20,75</sup> Young people are more likely to feel that their needs are being met in schools with a full-time appointed member of staff to support them for this purpose;<sup>20,38</sup> **however, one in three CYP have said they did not have a person at school that they could turn to with concerns**.<sup>20,76</sup> Those with more complex conditions say that they want to feel confident that their schools can meet their requirements.<sup>20,54</sup>

*'I think schools should have a care plan, setting out what to achieve for a year, for long-term conditions and have staff training for life-threatening conditions or some specialised training. Now most schools are dependent on families to come in and help... There should be an Ofsted category of how well the school is caring for the physical and mental health of the children.'* – Parent

**CYP with chronic conditions also highlighted the need for school support in helping them catch up with work that they miss while in hospital.** They wanted education in hospital to give them something to do and to prevent them falling behind, and for this to be integrated with education in their locality.<sup>38,51</sup>

*'I was ill over my GCSEs and the teachers kept saying where is she? But when I came back they never offered me any help and I missed over 50% of all my lessons. They didn't give me any work or help with my exams, eventually they even stopped asking where I was.'*—Young Person from a RCPCH focus group

School is also a setting where CYP with long-term conditions take medication. One study showed that for those taking regular medicine, accessing and storage of medication was not problematic; however, for 'as required' medication, there were barriers to access, including a lack of privacy.<sup>75</sup> Children with disability have said that they want support to access extracurricular activities at school as well as areas within the syllabus.<sup>20,77</sup>

## **Personal, social, health and economic education**

Young people want **the quality of personal, social, health and economic (PSHE) education to be improved**,<sup>17</sup> including suggesting that Ofsted inspect PSHE more effectively.<sup>78</sup> This was consistent with the views expressed by young people in the RCPCH and YoungMinds focus groups, who felt strongly that the structure of these lessons should be changed completely. They wanted PSHE to be taken more seriously; to be given more prominence in the curriculum, with lessons to be made mandatory, properly planned and structured; and for the content to be regulated. They suggested that lessons should include topics such as mental health, depression, preparation for employment, sexual health and healthy eating. The quality of PSHE lessons experienced by those in our focus groups was extremely varied, ranging from very successful programmes where students could choose from a range of interactive weekly sessions with external speakers, to those who were given the slot as 'a free period once a week'.

Some young people preferred specialist or external speakers rather than teachers to tackle all topic areas in PSHE<sup>78–80</sup> because of the sensitive nature of some topics and concerns about confidentiality. For example, in one study students appreciated being taught sexual health education by sexual health workers.<sup>40</sup> The young people from our focus groups also felt that health professionals would be beneficial or that peer educators, medical students, recovering drug addicts, teenage parents or volunteer groups could give valuable insights.

*'Music teachers should not be teaching PSHE; there should be a special teacher who does just this, or why not get a sexual health or mental health worker to come in?'* – Young person from YoungMinds focus group

The young people pointed out that they did not want to talk about sex or personal issues in front of their teachers whom they see every day. They felt that if teachers do run the sessions, they wanted them to be better informed, equipped and trained to deal with the topics. One of the parents interviewed had been a teacher who had taught PSHE in the past and said that:

*'It made for some uncomfortable moments, where students shared more than they might want to with me as they wanted to know more about sexual education.'*

Sex education was one area of PSHE particularly addressed by young people as so many were unhappy with the amount and quality taught in schools.<sup>38,81</sup> In a 2006/07 survey by the UK Youth Parliament, 40% of young people surveyed thought that their school sex education was either poor or very poor.<sup>78</sup> **Young women wanted sex education to be taught in single-gender groups with time for confidential individual sessions.**<sup>38</sup> CYP in our focus groups and in the literature were concerned that they were not getting the whole story about sexual education in schools; they wanted it taught earlier and for it to have a greater priority in the curriculum, with more issues covered, including detail about contraception, teenage pregnancy, sexually transmitted diseases, how to access their local sexual health clinic, gender crises and emphasis on relationships.<sup>38,81</sup>

*'Lots of people come in to talk about embarrassing things a girl can get, very few talk about embarrassing things that a boy can get! There needs to be more advice for boys.'* – Teenage boy from YoungMinds focus group

There was also some concern in our focus groups that many young people in religious schools around the country were not being taught sexual education at all and the young people agreed that: 'Even if they wouldn't give you the information in school they should tell you how to find it out.'

## **School nurses**

**Young people want their school nurse to be more visible<sup>82</sup> and to have more contact with them so that they become someone who knows you and whom you 'know and can trust'.**<sup>83</sup> Many young people reported that they rarely saw or knew their school nurse<sup>82</sup> and felt that they could not discuss issues such as sex and relationships with them.<sup>40</sup> CYP in the literature and in our focus groups suggested that assemblies, presentations and introductory sessions should be developed for all students on starting at a new school, to introduce the school nurse and their role, the service offered and how to access them.<sup>82</sup>

*'They should do health promotion, and be encouraged to lead assemblies, to teach the PSHE curriculum and be able to articulate or explain things we don't understand.'* – Young person in an RCPCH focus group

**CYP wanted a guarantee that their school nursing service is confidential,**<sup>82,83</sup> possibly even independent from the school, so that information would not be shared with teachers. They wanted easy access to the school nurse and waiting rooms where staff and other students could not see them, with the possibility of being able to contact the nurse directly by text, phone or email, without the need to tell their teachers.<sup>82,83</sup>

Some young people suggested being able to access the nurse outside school, for example at a youth centre, shopping centre or a local GP, to ensure anonymity, or for the nurse to be accessible outside of school hours.<sup>17,82</sup> The top five services that CYP have reported that they want their school nurse to provide advice on are: drugs; contraception; sexually transmitted infections; smoking cessation; and how to access other health services.<sup>82</sup> Other services CYP young people thought that nurses should provide included alcohol advice, mental health and wellbeing, confidence building, body image workshops and general health check-ups.<sup>83</sup>

Young people and the parents whom we spoke to valued the concept of a school nurse, particularly with regard to ease of access, confidentiality and not missing out on school time to access this form of healthcare, they also found the school nurse to be less intimidating than other health professionals. When asked to choose between funding for a school nurse or free school meals for all, as part of a priority-setting activity in our focus group, most of the young people said that a school nurse was more important.

### The views of specific groups of young people

In this section we explore the views on health and wellbeing of the four groups focused on in this report: children with neurodisability, mental health issues, looked-after children, and children in the youth justice system.

Issues important to these groups echo some of the general themes described above, including: lack of information about services and wanting more involvement in decisions about their own healthcare; ensuring that the health workforce is adequately trained to work and communicate with them; good relationships with health professionals; wanting to be taken seriously; the aspiration for integrated and co-ordinated care; and the need for good-quality transition services. It should also be noted that these are not discrete groups of children; for example, many looked-after children, and those in the youth justice system,<sup>65</sup> may also have a neurodisability or mental health problem.

### Children with neurodisability

There is much evidence in the literature on what CYP with neurodisability would like from their relationship with health professionals however, much of this is covered in the general section 'Child-friendly, personalised care' above. A predominant issue relevant to this group throughout the literature was the **lack of appropriate communication skills of health professionals**, for purposes of either consultation or participation.<sup>31,98</sup> They want clearer, child-friendly explanations and communication that is appropriate for their needs and disability.<sup>31</sup> As with CYP generally, **young people with learning disabilities do not like it when professionals use language they cannot understand or address their parents rather than them.**<sup>31</sup> They also want more involvement and explanation about procedures, including understanding why particular procedures are being done.<sup>31</sup> Overall, CYP with neurodisability want more training for staff on how to communicate effectively with young people with disability.<sup>31,45,77,98</sup>

CYP also want more support from health services to support them in being 'able to communicate to the best of their ability, encompassing a wide range of communication techniques and assistive technology to enable them to take part in the decision-making process'.<sup>99</sup> Parents of children with neurodisability and the young people themselves think that communication is an important aspect so that they can indicate their choices, be involved in decision making and controlling the management of their disease, and exert some independence, where 'not being able to communicate was a source of anxiety';<sup>99</sup> for example, they liked being able to manage their own medication.<sup>31</sup> They think that having someone to support them during their appointments, who they can ask questions of afterwards, or as an advocate would be helpful as they reach transition or move towards independence.<sup>31</sup> However, there was a fine balance with receiving too much support, which they felt could be disempowering.<sup>31</sup>

One approach that young people thought could increase their independence is having a health passport (hand-held records including information about them and their condition, and how they want to be supported to prevent them having to repeat themselves); another is enabling them to go to appointments independently.<sup>31</sup>

Many CYP with neurodisability and their families reported that **health services are not well integrated.** They are **not always given clear information** about how services interact, or how health services differed from each other in what they provide. They also feel frustrated about how they need to be persistent or have to 'fight' to get the services they need.<sup>45</sup> Another important issue is the time taken for diagnosis, which ranged from 3 months up to 15 years in one study. The need for continuation of care after leaving school to help them with further studies or a career was also highlighted.<sup>20,77</sup>

**Access to local health services can be a problem, especially for those in wheelchairs.**<sup>46</sup> A mother we

interviewed, who sits on many representative groups, said that access for referrals through primary care could be improved. Based on discussions with other families in parent groups, she recommended further training for GPs in the needs of their children with disabilities and in listening to parents' concerns. She said that it can be very difficult for parents of children with neurodisability to be taken seriously by health professionals as the symptoms begin to manifest themselves, and that 'jumping through the hoops for access' increases the anxiety for families. She highlighted the three key issues consistently mentioned by parents of children with neurodisability: 'the difficulty of getting into the healthcare system at the start, the need for good, integrated, co-ordinated care when you are in the system and the need for better transitional care'. She also talked about the support needed for parents of young people with neurodisability, especially the need for good sleep and exercise.

*'Family resilience is cropping up a lot in the disability world, the need to create resilient families as opposed to dependent ones.'* – Parent

### Children with mental health problems

CYP want mental health to have more prominence and to be a greater priority. They argue that mental health services should form a central part of all mainstream services for them, they want **'mental health to be taken as seriously as physical health'**<sup>51</sup> and for health and non-health professionals to be as confident in talking about mental health as physical health.

**Stigma was highlighted as a key issue for young people with mental health problems,**<sup>38,51,52,84</sup> **mainly as a barrier to their accessing services and support.**<sup>51,52,65</sup> Some young people are put off attending services because the word 'mental' is included in the title.<sup>51</sup> Young people were also concerned about the public perception of mental health issues. CYP who had never used mental health services before suggested that they were for people who were 'mad' or 'mental'.<sup>85</sup> **They want more health promotion campaigns and teaching in schools to counter the stigma associated with mental illness.**<sup>11,51</sup>

*'Stigma is bred into society from early experiences, children call someone a name because they are different; we need to educate people and normalise mental health issues.'* – Young person from the YoungMinds focus group

The literature shows that **who use mental health services want a confidential, accessible mental health service, when and where needed.**<sup>38,52</sup> This was echoed in our focus groups, especially the YoungMinds focus group. They want to be listened to, to know about different treatments, to be able

to give their consent to treatment<sup>38</sup> and for services to be age appropriate, with flexible opening hours at times that suited them.<sup>16,38,51,86</sup> Preferred referral methods include self-referral and drop-in services<sup>51</sup> available through the internet, mobile phones, text or email. A number of venues were mentioned, including at home, in clinics, in coffee shops, outside conventional mainstream health and welfare centres, or having a multiagency, multidisciplinary service to reduce the stigma associated with accessing mental health services, and to reduce the expense and time of accessing different services at different sites.<sup>11,16,51</sup> With regard to inpatient facilities, young people want interesting activities, education provision and support on discharge, as well as clean facilities with good food.<sup>38</sup>



**A happy boy (from a Kids Company workshop)**  
Source: Kids Company

Young people seeking mental health care want access to holistic services to improve all aspects of their lives and access to a range of help and support options,<sup>51</sup> including alternative treatments to medication. Many young people said that they felt 'fobbed off if they were only given medication, and weren't offered someone to talk to'.<sup>51</sup> This was reflected in our focus groups, where young people also said that

cognitive behavioural therapy, which is usually offered as standard, does not work for everyone.

*'The mental health system is very reactive, rather than proactive. It is more likely to respond to people in distress rather than respond to them before they get to that point; it feels like young people have to do something drastic in order to be heard and that shouldn't happen.'* – Young person from the YoungMinds focus group

Young people have said that they often feel as if they are not taken seriously when they talk about issues surrounding mental health and that professionals do not respond to them appropriately until they are very unwell or in crisis.<sup>11,51</sup> Young people have said in particular that they are often not given enough support at first presentation<sup>51</sup> and that **they often wait a long time to get support.<sup>85</sup> They want more support at first presentation, quicker access to help during an emergency, and better out-of-hours and crisis services, with inpatient units that are easier to access.<sup>51</sup>**

The quality of relationships with health professionals has been addressed as one of the most important aspects of care for CYP with mental health issues. Trust is a key issue.<sup>51</sup> Young people felt that they needed to trust the practitioner and build a relationship with them before they could talk openly about their problems; however, trust takes time to build and staff turnover, leave, shift patterns and being passed around services often obstructed this.<sup>11,51,85</sup> They want time to get to know staff and establish relationships.<sup>38,87</sup> **They want staff who are approachable, available and skilled in engaging and listening to young people.<sup>38</sup> Children and young people valued continuity, confidentiality and support, particularly at transition.<sup>86</sup>** Flexibility and accommodation of health workers to the young person's needs were seen as positive attributes.<sup>39</sup> Young people also want choice about their therapists, with the option to change practitioner if they want to.<sup>51</sup> They think that peer mentoring may be appropriate if support is given and it is managed well.<sup>85</sup>

For young people using mental health services, **lack of adequate information is a repeatedly highlighted problem.**<sup>20,38,51,52,88</sup> They say that the quality of information given to them about Child and Adolescent Mental Health Services (CAMHS), the illness and the treatment can be inadequate. Some young people report that they have been referred to specialist CAMHS without being given any information. Others have said that, although they were given all the information at the time, they could not take it all in as they were in too much turmoil.<sup>11,51,89</sup>

Young people from the YoungMinds focus group thought that teachers should be given more support to report any mental health concerns that they have for their students,

particularly very young children. They also wanted closer liaison between mental health services and schools, so that there could be mental health workers in schools or more collaboration of staff with CAMHS. **Many young people want access to counselling services within their school,** but others had reservations due to the stigma associated with going to a counsellor. It was suggested that a universal service such as the school nurse, where people did not know your reasons for attending, might be better.<sup>51</sup>

## Looked-after children

*'I have been through 56 foster places... sometimes when you are in looked-after care, the odds are stacked up against you, and then you add mental health problems to this as well.'* – 19-year-old female from the YoungMinds focus group

A key issue for looked-after children is the potential for frequent moves leading to discontinuity, and a lack of permanence and sense of belonging; looked-after children say that this can affect their sense of identity.<sup>64,90</sup> Children in care therefore particularly value stability of their placements and having continuity of care with one social worker and one key health worker with whom to build a trusting relationship.<sup>20,52,91-93</sup> Love, affection and a sense of belonging were desired but often lacking in the lives of looked-after children.<sup>90</sup> It should be noted, however, that the looked-after system can be very effective. In one recent study most children (97%) were happy and relieved to be with kinship carers. When asked where they would choose to live, 73% said with their kinship carer.<sup>94</sup>

CYP without parental support feel that they receive less information and advice on issues relating to health and health service access, particularly relating to: relationships; healthy lifestyle; sexual health; how to navigate the health system; how to register with a doctor or dentist; and entitlements such as free prescriptions.<sup>11,13,95</sup> **They also said that people did not always explain the details of their medical assessments so that they could not always understand why they were having them.**<sup>20,96</sup>

Some looked-after children face difficulties in using GP services and the literature shows evidence that care leavers can be very critical of their GPs, including feeling that they were not being listened to or that they could not discuss mental health issues with them.<sup>57</sup> They want social workers and other professionals not to make assumptions about the ease with which they could address sensitive topics.<sup>38,96</sup> They also think it is important that their teachers and youth workers understand key health issues to help them navigate the system and to explain things that they did not understand.<sup>25</sup> They particularly value speaking to older peers or health workers who have had personal experience of being in care.<sup>64</sup>

Looked-after children and young people in the literature **identified stigma and prejudice as being significant in their lives**.<sup>64,94</sup> They reported negative attitudes, curiosity and pity, and being singled out to feel different.<sup>90</sup> Those who had experienced stigma said it would 'affect their willingness to confide in friends at school or outside the care setting'.<sup>64</sup> Young people feel that there needs to be more widespread understanding of what it means to be a 'looked-after young person'. Participants say they are tired of telling peers that they are 'not like Tracy Beaker', a character from children's books and television, who young people feel is the only representation of children in care that others know about. They want some normalising of the concept of looked-after children, including the range of settings of care, to increase knowledge and alleviate some of the stigma attached.<sup>9</sup> A number of studies stress that children and young people in care want to be treated like other people and not singled out.<sup>20,91</sup>

Many young people in care were not asked their opinions on important matters or involved with decision making about their own care or health issues, leading to an 'overwhelming helplessness'.<sup>12</sup> Children in care want choice and control regarding their treatments, counselling or disclosure.<sup>64</sup> They want to be involved in the small decisions as well as the big ones, such as greater involvement in organising appointments and 'engaging meaningfully in their therapy'.<sup>18,20</sup>

**Young people in care also want more involvement in the review system.** Children in care did not like that they did not always know who would be attending their review and reported finding teachers attending when they could not see the relevance of this.<sup>12</sup> They have reported that they find it difficult to 'express themselves in review meetings and in court and want support with this, and they **value having independent advocates who can help them express their views and ensure they are heard**'.<sup>20,93,97</sup>

**Children in care say that they want adequate preparation for discharge from services.**<sup>20</sup> Where it was not done well, young people felt isolated,<sup>20,92</sup> and the transition from care 'triggered additional health problems or difficulties in maintaining their health... Some found this traumatic and were psychologically unprepared practically and emotionally for the transition'.<sup>90</sup> Looked-after children who had been through the process identified areas for improvement, including the need for more advice on how to manage their own healthcare, particularly at the time of leaving the care system,<sup>11,13</sup> and to not be required to move on until they were ready to do so.<sup>93</sup>

## Children in the youth justice system

In one study most young people entering custody said that they had very good access to healthcare on admission;<sup>100</sup> however, in a regular survey of young people's perceptions and conditions in custody, only 52% of young males and 60% of young females said it was easy to see a doctor, and only 32% of young males and 39% of young females

said it was easy to see a dentist.<sup>11,88</sup> Overall, girls rated the healthcare in their establishments lower than boys did.<sup>38,101</sup>

**Over a third of young people in custody interviewed for a study expressed feeling unsafe in their establishments at some point.**<sup>38,101</sup> A quarter of them said they had not received a visit from a friend or family member.<sup>38</sup> CYP said that being in custody would give them the opportunity to improve their health by eating well, stopping drugs and alcohol and by exercising, and they wanted support from their establishments for this.<sup>11,102</sup>

## Discussions with parents

Most of the comments from the parents have been included in the specific sections of this chapter. The key themes drawn from the interviews include:

- help for young people to gain independence in managing their own care
- services to be more child oriented
- more co-ordination, integration and consistency of care for individuals and across localities
- improved transition to adult services and for this to occur later (around age 24)
- schools to be more supportive of young people with long-term conditions.

*'One problem I see is that 18 year olds can't use GP services. It is hard for them to register on campus at university even though it is not complicated, as they don't feel engaged with the GP; it is something their parents have always had control over.'* – Parent

Parents also highlighted that it can be difficult to get their child into the correct health services and to be taken seriously initially by health professionals, although things become considerably better once they are in the system.

Parents were concerned about sending the right health promotion messages to the public. For example, two mothers who had daughters with type 1 diabetes said that people kept blaming their children for not having a healthy diet or exercising, but type 1 diabetes, unlike type 2 diabetes, is an autoimmune disease. There was also feedback that health promotion campaigns for young people should focus on the short-term effects as young people do not respond to warnings relating to long-term effects.

*'It is surprising that in this modern era hospitals are so behind in providing information to patients on their own websites... there is very little information about what they offer.'* – Parent

Some parents felt that there was insufficient support for new parents in the first weeks after birth and they were concerned that vulnerable families could 'fall through the cracks'. They also wanted greater support and more consistent messages from health visitors and for more information to be in the Personal Child Health Record (known as the 'Red Book'), including common medical conditions or conditions relating to mental health. One parent talked about the value of antenatal care that prepared you for life with the baby and not just for birth. One mother said that supporting families to build their own resilience would be important and wanted support to be offered earlier, as often families 'have to reach crisis point before interventions are put into place'. She also pointed out that building early relationships with parents during the antenatal period means that they are already involved with the healthcare system, and have already built up relationships with health professionals for when a child is ill or if more complex care might be needed.

One parent pointed out that, although it is good that the voices of children are being increasingly heard, these children are not in isolation and it is important to also 'speak to carers and the whole family as we are the ones that have to bear the brunt of the decision making'. She said that this was particularly the case for families with children with neurodisability, where some children cannot always vocalise their needs or make informed choices.

## Conclusion

In this chapter we have explored some of the key messages highlighted by children and young people in the literature and in our focus groups as being important to them. We asked all the young people in our focus groups what were the most essential aspects to include for this report. The main topics mentioned – which reflect much of what has been written in this chapter – were:

- need for better transition from children's to adult services
- improving the role of GPs for the health of children and young people
- better access to health services, particularly mental health services
- an improvement of PSHE education, especially sex education
- greater knowledge and practice of their confidentiality rights
- making health services more CYP friendly
- greater co-ordination and integration of healthcare
- increasing participation of CYP in health decision making
- the need for increased information about health services, including what to expect and how to access different services.

Children and young people clearly want to be involved in decision making on health and wellbeing issues, both on a national level and in relation to their own care, and many

of the ideas explored in this chapter are perceptive and insightful; there is clearly much we can learn from them. We therefore conclude this chapter with a **Children and Young People's Manifesto for Health and Wellbeing** – their requests and recommendations summarised from their voices throughout this chapter.

## A Children and Young People's Manifesto for Health and Wellbeing

### To improve their health and wellbeing, children and young people want:

#### ■ to be informed and have a say in decisions about their care, for example by:

- services providing child-friendly health information in places where children and young people can find it easily, such as in schools, clubs and on the internet
- having a directory of child- and young people-friendly services that they can consult and which can be used by health workers to signpost to relevant services
- receiving a printout or email from the doctor after their appointments with a summary of the key information discussed
- health professionals taking time to ensure that children and young people can give informed consent, including for procedures carried out on them when appropriate
- including young people in more national surveys about health, particularly hard-to-reach groups and children with disabilities

#### ■ to have personalised, child-friendly care from people they know and trust and who treat them with respect, for example by:

- health professionals, service providers and commissioners communicating and working together to ensure that services are co-ordinated and integrated, so that children and young people are not 'passed around different systems' and do not have to keep 'repeating their story' to each new health worker they meet
- having an advocate (e.g. the GP) to help them navigate the system and negotiate on their behalf
- having the opportunity to hear and learn from the past experiences of other young people
- health professionals, service providers and commissioners being seen to take mental health as seriously as physical health
- particularly for young people with mental health issues, more support at first presentation, shorter referral times, quicker access to help during an emergency, and better out-of-hours and crisis services, with inpatient units that are easier to access

#### ■ to have access to age-appropriate services where and when they need them, for example by:

- health professionals, service providers and commissioners listening seriously to and learning from the past experiences of other young people

- providing services in convenient, non-stigmatising locations, close to home and with flexible opening times, including weekends and early evenings
- having hospital wards specifically for teenagers and young adults

#### ■ to be supported through the transition to adult health and social care services, for example by:

- GPs and other health professionals working in partnership with the young person and their families or carers, where appropriate, to manage the transition process over a period of time and at a pace that is appropriate for the individual, with information, continuity of care and a clear handover to adult services
- health and social care professionals ensuring that looked-after children have the preparation they need for discharge from services
- supporting looked-after children to be more involved with their case reviews

#### ■ to understand their rights and responsibilities, for example by:

- policy makers ensuring that they provide information about the health policies applicable to CYP in child-friendly formats and in places where it can be found easily, such as through social media
- policy makers, health professionals and teachers helping children and young people to understand their rights to confidentiality
- healthcare and social care professionals and teachers showing due regard for children and young people's rights to privacy and confidentiality
- service providers and commissioners ensuring that children and young people are told how to make complaints about their care and are supported through the process

#### ■ for schools to play a greater role in health and wellbeing, for example by:

- schools supporting children and young people to help them catch up on missed work if they are absent for long periods of time due to a health condition
- schools playing a role in health promotion campaigns and encouraging healthy behaviours, including healthy eating health promotion campaigns
- improving the quality of personal, social, health and economic (PSHE) education, especially sex education, and including a wider variety of topics taught by health and social care professionals as well as teachers (e.g. to counter the stigma associated with mental illness).

## References

1. Department of Health. The NHS Constitution for England. 2013.
2. The Health and Social Care Act. London: HMSO; 2012.
3. The United Nations. Convention on the Rights of the Child. 1989.
4. The Children Act. London: HMSO; 1989.
5. The Children Act. London: HMSO; 2004.
6. Department for Education and Skills. Every Child Matters: Presented to Parliament by the Chief Secretary to the Treasury by Command of Her Majesty, September 2003, Cm 5860. London: HMSO; 2003.
7. Department of Health. National Service Framework for Children, Young People and Maternity Services. London: Department of Health; 2004 p. p7–8.
8. Department of Health, Department for Children, Schools and Families. Healthy lives, brighter futures: The strategy for children and young people's health. Department of Health and Department for Children, Schools and Families. 2009.
9. Department of Health. Improving Children and Young People's Health Outcomes: a system wide response. London; 2013.
10. Cavet J, Sloper P. The participation of children and young people in decisions about UK service development. *Child: care, health and development*. 2004 Nov;30(6):613–21.
11. La Valle I, Payne L, Gibb J, Jelcic H. Listening to children's views on health provision: A rapid review of the evidence. National Children's Bureau. 2012.
12. Burke T. Anyone listening? Evidence of children and young people's participation in England. *Participation Works*. 2010.
13. Blades R, Renton Z, La Valle I, Clements K, Gibb J, Lea J. We would like to make a change: Children and young people's participation in strategic health decision-making. Office of the Children's Commissioner. 2013.
14. Davey C. Children's participation in decision-making. A Summary Report on progress made up to 2010. *Participation Works*. 2010.
15. Adams L, Ahmed S, Bagnall J, Bateman J, Filsell S, Freeman S, et al. "Nothing about us, without us?": Young people and the future of the NHS. National Children's Bureau. 2010.
16. Children and Young People's Mental Health Coalition. Policy Briefing 3: Young People Involvement. 2010.
17. Ahmed A, Adams B, Kertesz C, Crockwell D, Gurbutt G, Mallion J, et al. Healthy Lives, Healthy People: Young people's views on being well and the future of public health: Consultation report on the Public Health White Paper led by NCB. National Children's Bureau. London; 2011.
18. Davies J, Wright J. Children's Voices: A Review of the Literature Pertinent to Looked-After Children's Views of Mental Health Services. *Child and Adolescent Mental Health*. 2008 Feb;13(1):26–31.
19. Moore L, Kirk S. A literature review of children's and young people's participation in decisions relating to health care. *Journal of clinical nursing*. 2010 Aug;19(15-16):2215–25.
20. Mainey A, Ellis A, Lewis J. Children's views of services: A rapid review. National Children's Bureau. 2009.
21. National Children's Bureau. Health structures, health information and patient involvement. NCB. 2012.
22. Day C. Children's and Young People's Involvement and Participation in Mental Health Care. *Child and Adolescent Mental Health*. 2008 Feb;13(1):2–8.
23. The National Children's Bureau. Bringing children and young people to the heart of Healthwatch: Reflections from LINks. NCB. 2013.
24. Hargreaves DS, Viner RM. Children's and young people's experience of the National Health Service in England: a review of national surveys 2001–2011. *Archives of disease in childhood*. 2012 Jul;97(7):661–6.
25. Department of Health. Report of the Children and Young People's Health Outcomes Forum. 2012.
26. Hopwood B, Tallett A. Little voice: giving young patients a say. *Nursing Times*. 2011;107(49-50):18–20.
27. Wood D, Turner G, Straw F. Not just a phase. Royal College of Paediatrics and Child Health. 2010.
28. Franklin A, Sloper P. Listening and responding? Children's participation in health care within England. *The International Journal of Children's Rights*. 2005 Mar 1;13(1):11–30.
29. Franklin A, Sloper P. Supporting the Participation of Disabled Children and Young People in Decision-making. *Children & Society*. 2009 Jan;23(1):3–15.
30. VIPER. Hear Us Out ! 2013.
31. Allard A. Managing my way. Council for Disabled Children. 2011.
32. Kirby P, Lanyon C, Cronin K, Sinclair R. Building a Culture of Participation. Department for Education and Skills. 2003.

33. Kirby P, Bryson S. Measuring the magic? Evaluating and researching young people's participation in public decision making. The Carnegie United Kingdom Trust. 2002.
34. National Children's Bureau. Children and Young People's Views on the 'NHS: An Information Revolution' and Local HealthWatch. NCB. 2011.
35. Graham J, Mitchell M, Day N, Lewis J. Young people's views and experiences of specialist substance misuse services. 2007.
36. National Children's Bureau. Teenagers' views on their health and local health services. NCB. 2012.
37. Robinson S. Children and young people's views of health professionals in England. *Journal of child health care: for professionals working with children in the hospital and community*. 2010 Dec;14(4):310–26.
38. National Children's Bureau. Children and Young People's views on health and health services. NCB. 2005.
39. Naylor C, Lincoln J, Goddard N. Young People at Risk of Offending: Their Views on a Specialist Mental Health Service in South East London. *Clinical Child Psychology and Psychiatry*. 2008 Apr 1;13(2):277–86.
40. Turnbull T, Van Schaik P, Van Wersch A. Adolescents' preferences regarding sex education and relationship education. *Health Education Journal*. 2010 May 4;69(3):277–86.
41. Taylor S, Haase-Casanovas S, Weaver T, Kidd J, Garralda EM. Child involvement in the paediatric consultation: a qualitative study of children and carers' views. *Child: care, health and development*. 2010 Sep;36(5):678–85.
42. Coyne I. Consultation with children in hospital: children, parents' and nurses' perspectives. *Journal of Clinical Nursing*. 2006 Jan;15(1):61–71.
43. Gibson F, SP et al. Cancer in young people: a narrative study to explore their experience from first symptoms to the diagnosis of cancer CLIC Sargent. 2009.
44. Gibson F, Aldiss S, Horstman M, Kumpunen S, Richardson A. Children and young people's experiences of cancer care: A qualitative research study using participatory methods. *International Journal of Nursing Studies*. 2010;47(11):1397–407.
45. Care Quality Commission. Health care for disabled children and young people. 2012.
46. Curtis K, Liabo K, Roberts H, Barker M. Consulted but not heard: a qualitative study of young people's views of their local health service. *Health Expectations*. 2004;7:149–56.
47. The Schools and Students Health Education Unit. Young People into 2013 [Internet]. The Schools and Students Health Education Unit. 2013 [cited 2013 Sep 16]. Available from: <http://sheu.org.uk/content/page/young-people-2013>
48. Moules T. 'They wouldn't know how it feels...': characteristics of quality care from young people's perspectives: a participatory research project. *Journal of child health care: for professionals working with children in the hospital and community*. 2009 Dec;13(4):322–32.
49. Brady M. Hospitalized children's views of the good nurse. *Nursing Ethics*. 2009 Sep;16(5):543–60.
50. National Children's Bureau. Promoting the NHS Constitution to Young People: Report on the Consultation Workshop 4 June 2010. NCB. 2010.
51. Lavis P, Hewson L. How Many Times Do We Have to Tell You? A Briefing from the National Advisory Council About What Young People Think About Mental Health and Mental Health Services. National Advisory Council. 2010.
52. Street C, Stapelkamp C, Taylor E, Malek M, Kurtz Z. Minority Voices: Research into the access and acceptability of services for the mental health of young people from Black and minority ethnic groups. YoungMinds. 2005.
53. Gibson F, Pearce S, Eden T, Glaser A, Hooker L, Whelan J, et al. Young people describe their prediagnosis cancer experience. *Psycho-Oncology*. 2013.
54. Marchant R, Lefevre M, Jones M, Luckock B. "Necessary stuff": The social care needs of children with complex health care needs and their families. Social Care Institute for Excellence. London; 2007.
55. Jerome S, Hicks C, Herron-Marx S. Designing sexual health services for young people: a methodology for capturing the user voice. *Health & Social Care in the Community*. 2009 Jul;17(4):350–7.
56. Barna D, Mckeown C, Woodhead P. Get Real: Sharing good practice in the provision of sexual health services for young people. Save the Children. 2002.
57. Clements K. Opening the door to better healthcare: Ensuring general practice is working for children and young people. National Children's Bureau. 2013.
58. Kennedy I. Getting it right for children and young people: Overcoming cultural barriers in the NHS so as to meet their needs. Department of Health. London; 2010.
59. Street C, Anderson Y, Allan B, Katz A, Webb M, Roberson J. "It takes a lot of courage": children and young people's experiences of complaints procedures in services for mental health and sexual health including those provided by GPs. The Office of the Children's Commissioner. London; 2012.

60. Brodie BI, Goldman R, Clapton J. Mental health service transitions for young people. Social Care Institute for Excellence. 2011.
61. Viner RM. Do adolescent inpatient wards make a difference? Findings from a national young patient survey. *Pediatrics*. 2007 Oct;120(4):749–55.
62. Shaw KL, Southwood TR, McDonagh JE. Young people's satisfaction of transitional care in adolescent rheumatology in the UK. *Child: care, health and development*. 2007 Jul;33(4):368–79.
63. Kirk S. Transitions in the lives of young people with complex healthcare needs. *Child: Care, Health and Development*. 2008;34(5):567–75.
64. Stanley N. Young people's and carers' perspectives on the mental health needs of looked-after adolescents. *Child & Family Social Work*. 2007 Aug;12(3):258–67.
65. Walsh J, Scaife V, Notley C, Dodsworth J, Schofield G. Perception of need and barriers to access: the mental health needs of young people attending a Youth Offending Team in the UK. *Health & social care in the community*. 2011 Jul;19(4):420–8.
66. Stanley N. Thrills and spills: Young people's sexual behaviour and attitudes in seaside and rural areas. *Health, Risk & Society*. 2005 Dec;7(4):337–48.
67. Datta J, Lanyon C, Read L, Sawyer E, Shaw J, Street B. Consultation with children with cancer, their siblings and parents for the NICE child and adolescent cancer service guidance. Commissioned by the National Collaborating Centre for Cancer. National Children's Bureau. London; 2004.
68. Ingram J, Salmon D. Young people's use and views of a school-based sexual health drop-in service in areas of high deprivation. *Health Education Journal*. 2010 May 4;69(3):227–35.
69. Carroll C, Lloyd-Jones M, Cooke J, Owen J. Reasons for the use and non-use of school sexual health services: A systematic review of young people's views. *Journal of Public Health*. 2012;34(3):403–10.
70. Heaton J, Sloper P, Clarke S. Access to and use of NHS Patient Advice and Liaison Service (PALS): the views of children, young people, parents and PALS staff. *Child: care, health and development*. 2008 Mar;34(2):145–51.
71. Heaton J, Sloper P. National survey of Patient Advice and Liaison Services (PALS) in England: children, young people and parents' access to and use of PALS. *Child: care, health and development*. 2004 Sep;30(5):495–501.
72. National Children's Bureau. Have your say about the Government's new Child Health Strategy: A report on the findings from NCB's on-line survey with children and young people on health and well-being. NCB. 2008.
73. Davey C. What do they know? Investigating the human rights concerns of children and young people living in England. Children's Rights Alliance for England. London; 2008.
74. Pearce A, Kirk C, Cummins S, Collins M, Elliman D, Connolly AM, et al. Gaining children's perspectives: A multiple method approach to explore environmental influences on healthy eating and physical activity. *Health & Place*. 2009;15(2):614–621.
75. Smith FJ, Taylor KMG, Newbould J, Keady S. Medicines for chronic illness at school: experiences and concerns of young people and their parents. *Journal of Clinical Pharmacy and Therapeutics*. 2008 Oct;33(5):537–44.
76. Madge N, Franklin A. Change, challenge and school nursing. National Children's Bureau. London; 2003.
77. Lewis A, Davison I, Ellins J, Niblett L, Parsons S, Robertson C, et al. The experiences of disabled pupils and their families. *British Journal of Special Education*. 2008 Jan 14;34(4):189–95.
78. UK Youth Parliament. Sex Relationships Education: Are you getting it? 2007.
79. Coombes L, Appleton J V., Allen D, Yerrell P. Emotional Health and Well-being in Schools: Involving Young People. *Children & Society*. 2013 May 18;27(3):220–32.
80. Bourton V. Sex education in school: young people's views. *Paediatric nursing*. 2006;18(8):20–2.
81. Formby E. Sex and relationships education, sexual health, and lesbian, gay and bisexual sexual cultures: Views from young people. *Sex Education: Sexuality, society and learning*. 2011;11(3):255–66.
82. British Youth Council. Our School Nurse: Young people's views on the role of the school nurse. BYC. 2011.
83. Moxon D. "Someone you know and can trust": Consultation with Young People on the future of School Nurses. North West Regional Youth Work Unit. 2011.
84. Right Here. Literature Review: young people aged 16 to 25: the promotion of mental health and well-being and the early intervention in mental health problems.
85. YoungMinds. Improving the mental health of Looked After Young People : An exploration of mental health stigma. London; 2012.
86. Coad JE, Shaw KL. Is children's choice in health care rhetoric or reality? A scoping review. *Journal of Advanced Nursing*. 2008 Nov;64(4):318–27.
87. Lester H, Marshall M, Jones P, Fowler D, Amos T, Khan N, et al. Views of young people in early intervention services for first-episode psychosis in England. *Psychiatric services (Washington, D.C.)*. 2011 Aug;62(8):882–7.

88. Summerfield A. Children and Young People in Custody 2010–11. HM Inspectorate of Prisons, Youth Justice Board. 2011.
89. Rani J, Prosser A, Worrall-Davies A, Kiernan K, Hewson L. User and carer views of CAMHS intensive home treatment service in Bradford. *Practice Development in Health Care*. 2009;8(4):223–38.
90. Dickson K, Sutcliffe K, Gough D. The experiences, views and preferences of Looked After children and young people and their families and carers about the care system. Social Science Research Unit Institute of Education, University of London. 2009.
91. Barnardo's. *Failed By The System: The views of young care leavers on their educational experiences*. Barking; 2006.
92. Barn R, Andrew L, Mantovani N. *Life after Care: The experiences of young people from different ethnic groups*. Joseph Rowntree Foundation. York; 2005.
93. Morgan R. *Children's messages on care: A report by the Children's Rights Director for England*. Ofsted. London; 2007.
94. Farmer E, Selwyn J, Meakings S. "Other children say you're not normal because you don't live with your parents". *Children's views of living with informal kinship carers: social networks, stigma and attachment to carers*. *Child & Family Social Work*. 2013 Feb 3;18(1):25–34.
95. Cafcass. *Cafcass Health and wellbeing review: The experiences of young people in care*. London; 2008.
96. Dobel-Ober D. *The views of looked after young people about health and health care*. National Children's Bureau. London; 2005.
97. Timms JE, Thoburn J. *Your Shout! A survey of the views of 706 Children and Young People in Public Care*. NSPCC. London; 2003.
98. Shilling V, Edwards V, Rogers M, Morris C. The experience of disabled children as inpatients: a structured review and synthesis of qualitative studies reporting the views of children, parents and professionals. *Child: care, health and development*. 2012 Nov;38(6):778–88.
99. Morris C, Janssens A, Allard A, Coon J, Shilling V, Tomlinson R et al. *Informing the NHS Outcomes Framework: what outcomes of NHS care should be measured for children with neurodisability?* *Health Serv Deliv Res* 2013; in review.  
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100. Worsley R. *Young People in Custody 2004–2006: An analysis of children's experiences of prison*. HM Inspectorate of Prisons and the Youth Justice Board. 2006.
101. Challen M, Walton T. *Juveniles in custody: a unique insight into the perceptions of young people held in prison service custody in England and Wales*. HM Inspectorate of Prisons, Youth Justice Board. London; 2004.
102. Lewis E. *Healthier Inside: Improving the well-being of young people in secure settings*. National Children's Bureau. 2007.

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