

# CHILDREN AND YOUNG PEOPLE

## INTRODUCTION

Children and young people are not just smaller adults. Their bodies and minds, and associated health and care needs, are different and distinct, requiring a dedicated, expert and age-sensitive approach. The English health and care system is not fully adapted to this reality. Though the role of paediatricians is generally prized and at its best ensures a personalised, age-appropriate, child-centred and holistic approach to secondary medical care, overall quality is variable. In the UK, health visitors focus on prevention and support for parents of 0–5-year-olds, which is a cornerstone of World Health Organization (WHO) primary healthcare policy (WHO, 2008). The people who work in this service have recently experienced a significant drop in numbers, restrictions in mandatory scope, policy flux in relation to their role, and structural distancing from their family doctor colleagues, to the extent that one GP recently said that health visitors were “out there somewhere”, but exactly where was a mystery to him (Bryar et al., 2017).

The NHS Long Term Plan in England (NHS, 2019) acknowledges improvements in some services in England but gives a mixed picture overall. A number of child health outcomes lag behind those in other comparable countries (though social and economic factors such as poverty and deprivation play an important part in this too). There are particular problems with mental ill health, mortality (including neonatal deaths and deaths from respiratory conditions such as asthma) and obesity. Children from deprived areas or with a black or minority ethnic family background are twice as likely to be obese as those from other backgrounds, and this inequality is widening (Public Health England, 2018).

Children with complex needs and disabilities are often under-served, with parents struggling to access help and support for their children, especially from local authority social services and education departments, and to achieve coordination between different services (Council for Disabled Children, 2019). Anxious and exhausted parents often find that the system does not respond well to their own needs as carers (Smith et al., 2015). The transition from child to adult services can be fraught and lead to discontinuities of care (Colver et al., 2019).

In recent years there has been growing awareness and concern about the level of mental ill health among children and young people and the extent to which the NHS is able to cope (King's Fund, 2017). A survey of young people published in 2019 by the Royal College of Paediatrics and Child Health highlighted calls for quicker referrals, better staff training, better mental health support, more focus on equipping young people with self-care skills, and closer listening to young people in decisions about individual care and services (Royal College of Paediatrics and Child Health, 2019). Under the Long Term Plan, the NHS has committed to improvements in child health services across a broad front, including more integrated services, the move to a 0–25-year service and better provision for young people with autism and learning disabilities.

## THE STORIES

As with the other chapters, we invite you, the reader, to immerse yourself in the stories and then reflect. In Chapter 1 (Section 2, p. 4) we offer an understanding of patient-centred care in general as:

- Understanding and valuing what matters to patients
- Seeing the whole person
- Respecting people's rights and autonomy
- Being customer focussed

At the end of the chapter, we have posed a few questions arising from the following stories. We have tried to do this in such a way to provoke rather than to constrain your own thinking. As a patient or carer, a healthcare professional, an NHS manager or anyone else with an interest in child health, what issues are raised by these testimonies? What can be done and what can you do to improve the way that care can be organised around children and young people – and their carers?

Four contrasting stories are presented here. **Dan** is a normally healthy teenager who was hospitalised with an acute bacterial infection from

which he has now recovered. His father Jonathan tells the story from his perspective. Dan's illness took place during the COVID-19 pandemic, and some of the features of his care and treatment reflect changes to NHS services which were necessitated by the pandemic. **Jim** was a severely disabled young man from birth until his death aged 36. His parents Justin and Lucinda cover his entire life – and death – in their account. In a story fragment, **Eve** remembers how as a child she came to be diagnosed with Type 1 diabetes. Finally, the story of **Finbar** is related by his mother, who tells of her experiences as a carer for her teenage son with a diagnosis of scoliosis, including the length of time taken to get an appropriate tertiary referral, and the need to track and chivvy to get appointments and get the operation scheduled. Her experience of a support group was very helpful to her.

### *Story 3: Dan and Jonathan*

16-year-old Dan began complaining of back ache one Friday evening following a bike ride during the COVID-19 lockdown. The symptoms worsened over the next several days, with Dan suffering pain, loss of mobility, poor sleep, swollen joints and eventually jaundice. His father Jonathan sought help from NHS 111 and the local GP surgery. Though he was impressed by the swift response of both services – Dan was prescribed powerful pain and sleeping medication – these did not seem to be working. A week after the initial onset of symptoms, Jonathan made a repeat phone call to the local surgery and a GP asked him to bring Dan in. There were many examples of care and kindness. At times Dan's parents were overwhelmed by the amount of information they were given, and it was not always clear who was in charge on the ward.

**Jonathan:** So we went in and we were the only patients there and I couldn't help noticing how bizarre it all was to go into a GP surgery where there is no one there and then the GP saw us and he had, you know, enough time to do a thorough investigation. He didn't know what it was. And he said, "I want to book you in for some blood tests." And he said, "In the meantime if it gets worse and you are really worried, go straight to A&E." And he said, "Don't worry about going to A&E during lockdown because this doesn't look like COVID so you'll go to a non-COVID part and actually they're really quiet up there." In fact – and he made a bit of a joke about this – "they are dying to see people, they'd love it if you turned up." We had a bit of laugh about it because this

seemed so bizarre for any doctors kicking their heels waiting for patients to turn up.

On the Sunday, still worried, Jonathan did take Dan to A&E. It was very quiet and they were seen immediately. Tests were done and in the absence of a definitive diagnosis Dan was admitted to the paediatric department, where he spent the next three weeks. During the first few days:

**J:** We were sort of bombarded with information and tests and investigations. It was quite a bewildering and anxious time. He was in the care of the paediatric department. He also came under the attention of the orthopaedic department because of all the joint pain and mobility issues. He came under the attention of the cardiologists because they were worried that he had a bacterial infection that could get to the lining of the heart and cause something called infective endocarditis. And also the infectious diseases department. And then during that period also they did some scans and so the radiologists were involved and they found a big abscess on a muscle and they then operated on it. During that time they found he had a bacterial infection – a staphylococcus aureus infection – they thought it had caused the abscesses. They didn't know whether other things were going on as well, they couldn't quite explain the jaundice. They thought that might have been caused by all the medication he had been on.

An added complication was the COVID-19 pandemic.

**J:** They also did a COVID test on him. In order to do that they took him and put him in a different ward in the COVID section of the hospital, which alarmed my wife – well, we were all alarmed because we couldn't see the logic of it. My wife tells a story about how she sat in a chair to stop people coming in because she was worried about COVID infection and she was paranoid about it and she couldn't understand why she hadn't been tested even though Dan had been tested. And he was there I think for about forty-eight hours until he got the all clear and then he went back to his previous bed in the paediatric ward. It was all very weird: the parents were never tested and we could come and go, and so the COVID procedures seemed to be somewhat haphazard.

Then I said to my wife, "Look this is mad, you need to come home and have a rest." And from then on we did a rota so that we alternated every twenty-four hours and so one of us was there overnight. The first week was the most alarming because they put him on antibiotics, a very

high dose. What they said was ... of course we were Googling like mad as you do ... but the most dangerous thing that could happen really would be an infection of the heart lining and that could be fatal, so they were zapping him with antibiotics. Then they made a decision that they could reduce the dosage and over that week, they became less worried about his heart but they were still worried about the fact that it was taking a long time to kill off the infection and so he had daily bloods, and the level of infection was going down but it hadn't been eliminated and what they said was they want to kill it off completely and from the point that it's a negative test, they then want to give him two weeks of intravenous antibiotics and then they can send him home and he has four weeks of antibiotics taken orally. So in other words, they were taking absolutely no chances with this bug.

In the first few days Dan was bedbound and needed a lot of hands-on care.

**J:** This was one of the reasons why we felt instinctively that we had to be there. He got very hot, he needed to be rolled over, he needed to be fanned, and in fact we had to bring in a fan as they didn't have one. He needed cold towel washes. The other big part of the first two weeks was draining the abscess and having this tube hanging out into a bag while it continued to drain for several days. When we rolled him over we had to keep making sure that we weren't trapping the tube that was draining from his upper thigh into this bloody horrible bag.

Also, he needed to wee into a bottle and have it emptied. One of the weird things was that we know him as a fully post-pubescent 16-year-old, 6 foot 6 boy, who in normal circumstances, would totally, you know, protect his privacy and dignity. Lying there naked because it was too hot to wear clothes and he hated the hospital gown, I would sort of try and look away as he was weeing into his bottle and then he would say, "Yeah, forget it, Dad, it's okay, my dignity has gone out of the window, it doesn't really matter now," and he was really quite cool about it.

*Supposing you hadn't been there, what would've happened? I assume he would have had to call the nurse or somebody?*

**J:** We would have been very worried about him and whether he was getting the care that he needed. As it was, he was calling them quite a lot. The IV machine would beep all the time, it would beep to warn you it was going to end and it beeped when it did end. Or it beeped because it said there was a blockage. So quite a lot of time was spent calling the

nurses to come and turn the machine off or fix the problem or, you know the infusion is ended. One of the things we learned was, when the infusion is ended, it's fine, you are not going to suddenly get pumped full of air in your veins and die of an embolism. It took a while before we got a proper explanation and we still worried about it as occasionally air bubbles would appear. And we'd think, "Is this serious, should I call the nurse?" It's funny, Dan was quite happy to call the nurses and be a demanding patient. Whereas I often felt that I didn't want to disturb the nurses, so he was quite a good advocate for himself – probably better than I was.

*Interesting. Why do you think there was that difference?*

**J:** Oh, he's a teenager, lacks deference. He was very charming, he's got quite a way about him. He was completely unabashed about calling for help. The nurses really liked him but he was calling them all the time. That could have been reduced if instead of having a machine that beeps by the ear of the patient and their worried parent, you had a machine that alerts the nurse in the place where the nurse is.

The family had to digest a huge amount of information.

**J:** One of the issues was there's an awful lot of information to absorb. We saw the orthopods and the paediatricians and the radiologists quite a lot. They were very good at doing their best to convey lots of information about what they thought was happening, what the treatment plan was and what was going to happen next. It was very patient-centred and very parent-centred. But it was very difficult to make sense of. Both Marianne and myself were taking notes just in order that we could go back and look at what was being said if there were any problems later. It's not because we didn't trust them. There was almost too much information. I mean, we probably didn't help by asking lots of questions and trying to make sense of it all. Their willingness to explain, I thought, was really good, I couldn't fault it. But it was all quite confusing.

*Did Dan say he thought it was a bit much as well?*

**J:** Yes, at one point, he did say, "There's just too much information." And it may be partly because they were always talking in the presence of Dan and he's a minor and so they are probably thinking that I need to explain this quite thoroughly and carefully to somebody who is a

child. So they maybe could have done more checking on information needs; I think that's a more sophisticated approach.

So, after the first week of anxiety, we got the news that the germ had been killed off and the blood cultures were negative. That was a big turning point and we were able to relax. It was only at that point, where I think the paediatrician said, "Actually we've been quite worried about how long it took to kill off the infection, it normally takes forty-eight hours and this took about a week." And so they hadn't shared all their worries with us and actually I was glad as we had enough worries.

*Can I ask about that? The received wisdom is that you shouldn't hold back from sharing with family what's going on, but on this occasion you felt this was the right call?*

**J:** Well, it was in a context of relief that things were okay. My thought was, well, actually I'm quite glad that you didn't burden me with that extra worry as I was worried enough already. It's not as if they weren't telling us quite a lot. So, yes, it made me reflect on my own need for timely and accurate information. You have to make a judgement about it, I think, based on what you think the expectations of a parent are.

Dan was delighted by unexpected visits from the A&E staff.

**J:** At various times, all three of the clinicians who had been on duty when Dan came into A&E – the nurse, the consultant and the junior doctor – came up to visit. And of course it was very quiet in A&E but nonetheless, the fact that they'd made the effort was absolutely lovely. It was just a spontaneous demonstration of caring. They didn't have to.

*Do you think there's also an element, because they were quieter because of COVID-19, there was a kind of medical curiosity as to what was going on with that?*

**J:** I'm sure they were curious because he was an interesting case. I don't mind that.

*How did Dan react when they came up and said how are you getting on?*

**J:** Ah, he was overjoyed. He was really chuffed and he liked them, they all had a really good rapport. This is paediatric A&E, so I guess they are predisposed and selected on the basis that they are good at relating to young people. But they were ... all three of them were just really nice.

*Can you tell me how important that was for you and Marianne and for Dan that they did that, made that journey from the first to the seventh floor?*

**J:** There was just something about the sense that he'd been remembered. It said something about continuity, about people aren't just looking after you because you've ended up in their patch, they actually think about you when you're not there, and come and seek you out. It's not something that you'd expect or demand as a matter of course. Indeed, in most cases it just wouldn't be practical, but it was just a lovely bonus.

Though Jonathan's assessment of Dan's care and treatment is overall very positive, there were a number of irritating aspects.

**J:** People were always asking him how tall he was. A paediatric patient of 6 foot 6 is a bit of rarity and I think people were curious and enjoying his rarity value but he got a bit bored ... actually he did get a bit fed up with that. Strictly speaking, you know, when everybody's doing it, it starts to feel as though people aren't respecting you.

*It's quite insensitive, actually. It could be perceived as that after a while.*

**J:** I think he took it in good part and it wasn't such a big deal for him but I think from time to time I got the sense that he found it slightly irritating. People can be sensitive about their height, not all tall people enjoy being tall. Actually he's fine with it but, you know, people have all kinds of body issues. How could they know he wasn't sensitive about his height? So for me that felt a bit off.

Jonathan has a number of observations about the nursing.

**J:** The nursing staff were interesting because it was actually quite difficult to work out what status and authority the different nurses had. I think there is a colour coding in the uniforms. It was never clear. There was never the equivalent of what the consultants did. They would tend to introduce themselves and say, "Hi, I'm a consultant this and I'm a consultant that and my name is so and so." Whereas the nurses would tend to introduce themselves by their first names and say, "Hi, I'm so and so and I'm on duty tonight," but it wasn't always clear how senior they were and how much authority they had. You want to know who's in charge.

In the entire time we were there, which was three weeks, we encountered one senior nurse in the "classic" style, which people of my age are



used to. She was of a certain age, she must have been in her late 40s or early 50s, and she had a very authoritative manner, she told you exactly what was going to happen and exactly what she was going to do, and she went about things in a brisk and efficient way and created waves of calm and reassurance around her. Whereas most of the nurses seemed fresh out of college, they all seemed so incredibly young and it just wasn't clear how much skill and experience they had.

And from time to time, you did wonder when they, for example, fumbled with taking blood or fumbled with changing a cannula ... Almost comically, because Dan had this huge abscess on one of his toes (a bizarre thing) which then got drained painfully and then needed to be dressed, the only people who seemed to be able to dress this damn toe were the orthopaedic doctors, but they had this habit of coming along and undoing the dressing every time they investigated it to check how it was doing and then leaving it undressed and then assuming that a nurse would do the dressing.

Then generally speaking, a nurse wouldn't do the dressing unless we'd ask and some nurse would do the dressing and it would fall off again. It became a point of comedy between us about how rubbish the nurses were at doing dressings. Particularly as Dan got out of bed and started to mobilise, the first thing that would happen was his toe dressing would fall off.

I think, how hard can it be, isn't that basic nursing? What is going on here? I can't think of a nurse who wasn't kind and caring. But they weren't always good at the basics, and the other basic thing was that sometimes Dan was in a lot of pain and needed pain relief. You know, we just wanted it to be delivered quickly and not to have to go and pester the nurses for it.

Jonathan also reflected on the difference in status and authority as between the nurses and doctors.

**J:** The doctors were the ones with daily visits and daily information, often with the results of blood tests that had been done the previous day. They came with revised treatment plans or confirmed treatment plans and the sense that we got was that the doctors are in charge and the role of the nurses implicitly was one to just execute whatever decisions the doctors had made. There was no sense that the nurses had any independent authority to do anything in particular. Even though they may have done, that was never clear to us. The doctors are the people who turn up when they turn up and you have no means of getting hold of them. They turn up on their ward rounds and they tell you stuff. The

nurses are the people you can call with your buttons, so they are like servants who can be called. It's very interesting how the work practice and the design layout also send messages about who is in charge.

The doctors come in their own time. The nurses, at least in theory, are there to be called in your time although they don't always respond in the time that you want. But it is interesting how that sends a signal, doesn't it, about the relative status of doctors and nurses.

And a final reflection on the intravenous infusion pump:

**J:** The beeps are noisy and intrusive and can be alarming and they are not heard by the nurse so you always have to call a nurse to turn the machine off. And if you know you are infusing somebody you'll know how long it lasts because the machine is programmed to do it for thirty minutes; even if you can't hear it, then you should be back in thirty minutes in time to turn it off. In practice, the nurses needed to be called and I am happy to give them the benefit of the doubt that it was because they were busy with other patients. In which case the problem was a technical one, which is if you've got a machine that is going to send reminders to people that they need to take some action then the reminder needs to be directed to the person who needs to be reminded, which is not the patient and not the carer, who are not in a position to do anything about it and it may just make them more anxious.

#### *Story 4: Jim, Lucinda and Justin*

Jim had physical and learning disabilities from birth, and associated health and behavioural problems. He was diagnosed with Robinow syndrome, a rare genetic disorder. He lived with his parents Justin and Lucinda until his death aged 36. He also had a younger sister Rosemary. His parents explored residential care options for Jim when he was younger but decided that having him at home was the best option. During his life he and his parents had many interactions with NHS and social care services. His parents spoke about Jim a few months after his death.

**Lucinda:** When Jim was born I didn't think anything was wrong. Before he was born I had a scan and I read the results (I shouldn't have done but I did) and it said that the baby had a big head. And when I went down to see the doctor to share the scan, I mentioned that and he said, "Oh, babies' heads are different shapes, lots of babies have big heads,"

and so I didn't really think it was going to be a problem. When Jim was born, he was born very quickly. I didn't have time for any drugs at all and he was very small and of course I didn't realise anything was wrong except everyone's faces and an air of panic in the room. When Jim was delivered we thought we had a little girl and when I held him I realised there was something dreadfully wrong. He had an enormous head and a tiny, tiny body.

And we went to a normal ward and everyone was having visitors and celebrating having a baby and I got very upset and asked if I could be moved. And then they provided a side ward and I went on my own. And then a very good young doctor came, a lady, and she was lovely. We had a consultant. He did lots of tests, but straightaway he said that this child isn't Downs because you can see the lines of his palms. And I only saw him the once, I think. Over the next few days we had another consultant called Dr X, who was our consultant for over eighteen years, I think.

That was great. We used to visit him in XXX and he was very supportive, did lots of research.

**Justin:** At that time you had to bear in mind that the number of documented cases of his syndrome were very, very few indeed and were in America. So information was difficult to come by as it was pre-Internet. There are many, many more documented cases now than there were. They're mostly in America and he's not typical in any case because he has other issues that are not specific to Robinow syndrome, which is what he had, having been the name of the person who identified it initially.

It's worth mentioning here his genitalia was not specific. In other words, it looked as if his penis was more like a clitoris than a penis and he had no testes as well; there was no evidence of a scrotum and so on. So it was difficult.

*So Dr X provided that care and support over eighteen years?*

**J:** Until Jim stopped being a child effectively and became an adult.

*What difference did that make to you?*

**L:** Huge difference. He was just a very kind person.

**J:** He wasn't a specialist other than the fact he was a paediatrician. He wasn't particularly familiar with children with disabilities. He'd obviously had children under his care that had disabilities but that wasn't his specific specialism, as far as I know.

*And that didn't bother you, that wasn't particularly important to you?*

**J:** It was such a rare syndrome there wouldn't have been anybody like that available in any case, certainly not locally. I mean, the prognosis about his life generally at that stage wasn't particularly good in any case. I think twice we were called to XXX as they said, "You'd better come to the hospital straightaway," and he pulled through.

In terms of social workers, I don't know where to start, really, with that because, over the years we had a whole stream of different people; they didn't seem to stay with the service very long, some were better than others and some were completely useless.

**L:** I think we were fortunate because we were transferred to XXX maternity home. It was a very small unit and I think there were three of us on the ward and you could stay on the ward as long as you wanted to, pretty much. And that was lovely because at that point Jim was having tests to see his gender. We were told that we could decide if we wanted him to be a girl or boy. The staff there, I remember, the nurses were very supportive and they were very kind. Do you remember, Justin?

We decided that he'd be a boy and it was all a bit confusing for people because we'd said we'd had a girl. I don't know how we got round that. The medical practice in XXX were really good, GPs would come out if we needed.

**J:** Of course the GPs would come out to you in any case at that time. It was that era. And Dr X was a very kind and gentle person.

*The GPs and paediatricians didn't know much about Robinow syndrome, but that didn't matter particularly did it, I guess?*

**J:** No, because any problems that he had were not related to the typical case of Robinow syndrome. There were other issues that he had. He had breathing difficulties, he had a restricted oesophagus and windpipe. He had issues with swallowing and breathing. It could have been anybody, really.

Jim spent much time in hospital as a child. The care was mostly good but his parents describe one bad incident.

**L:** Yes, it was in the children's hospital, actually, and Jim had a hernia when he was quite small. We went into the room and the doctor that was going to do it asked if he could bring some students in and I said yes. And then they took Jim's pad off and he said to them, "You've never seen anything like this before and you never will again."

**J:** And you were upset. People engaging mouth before engaging brain about the impact it's going to have. It's all right saying that to students, but when the mother's there as well, it was a bit unthinking, wasn't it?

*Was there any sense from looking at his face or those of the students that they had an understanding of that impact?*

**L:** Yeah, I think the students did. I don't think he did. They were embarrassed.

Lucinda and Justin describe Jim's health problems and disabilities.

**J:** He had some mobility issues which were ongoing. I mean, over the years he could walk better if he was inclined to do so. He was only the same size of a 9-year-old. So he was small in stature. The other difficulties were feeding. Initially he would have everything done for him but he did get to the point at one stage where he would drink from a bottle with a teat on. But then we were advised not to do that by the health visitor, because we were giving him sugary drinks and that could give him tooth decay over a period of time, blah-de-blah. He had difficulty swallowing because his oesophagus was constricted and so the food had to be chopped up very small. And this got worse as the time went on. I mean, naturally we had to blend all his food to soup-like consistency. That was partly due to the restriction in his tubes but also because he developed a problem with acid indigestion, acid reflux. The stomach valve didn't work properly and so he'd get food coming back up and an acid which burnt his throat. And then, obviously, it was a bit of a vicious circle because he didn't want to eat as it hurt to swallow.

So we went to see a gastro specialist in XXX and the first one was useless, wasn't he? He said had we tried doing, this, that and the other. He was just very unkind. He said, "He might be bringing stuff up because you are making him swallow it too much at a time." There was all sorts of things. Anyway, in the end, we did actually say to the hospital could we see someone else and we saw somebody who was much more sympathetic.

Well, he prescribed some medication to help with the reflux, which he was on until he died. But that situation got worse and worse and he would vomit, especially if he was lying down. He was less likely to vomit when he was vertical than when he was horizontal. So we had to keep his head raised in bed eventually and things like that. I mean, we got up – I don't know – innumerable times we had to get up in the night, sometimes two or three times in the night to go and change him and

his bedclothes because he'd vomited. This was all due to this acid reflux band so the drugs were only partially effective. He was always having problems with lumps in his food, you know, we had choking incidents in the past when I've had to do a Heimlich or turn him upside down and pat his back and stuff.

*And he had speech and language difficulties, didn't he?*

**L:** No speech at all.

**J:** He understood a lot more than he could convey to you. The noises he made would give you an indication of his moods. He could laugh, he could cry and those types of emotions. He could express pain but there was nothing we would call intelligent about the noises that he made unless you understood him like we do.

**L:** He was doubly incontinent.

**J:** Oh yes, there was all that. Right the way through his life. We did try to train him to use the toilet but it wasn't possible. We tried and tried and we just had to give up in the end.

**L:** At the end of his life, we seemed to have lots of therapists. We had a speech therapist. What else did he have, Justin? He was partly deaf in one ear, more than he was in the other ...

**J:** We saw somebody that was organised by that nice speech therapist who told us why he couldn't drink from a beaker and things which no one had ever told us before. Because he had problems with his jaw. His bottom teeth overshot his top teeth, which made chewing difficult and it also made drinking difficult. We never realised why he was so reluctant to drink other than from a spoon. We had at least two speech therapists before that. And also we got advice about feeding from the speech and language therapist department as well. Some of which was better than others, you know. You don't know until you try these things.

Justin and Lucinda describe the problems of hospital admissions once Jim had become 18.

**L:** That brought its own problems because then we had to go into main-stream hospital and he'd be on a ward with adults, which was awful. It was at Christmas, Christmas morning, and he'd had gastroenteritis and he was rushed in and he was taken into an adult ward. I got so cross because they really were not looking after him, expecting me to do everything, and I was in a state and you just wanted a bit of help and advice, really. I remember being very upset about that.

**J:** Throughout, it's always been a struggle because every professional that has had any dealings with us, and with Jim, treat him as his real

chronological age. There was no allowance made for the fact he was still basically a child. All his life he was a child. He never progressed from being a child mentally. And physically he looked like a child with his stature being so small. That has been an issue time and time again.

Later experiences in other hospitals were better. Over the decades, Justin and Lucinda felt that the hospitals improved their understanding about how to deal with disability. They reflect on a particularly good social worker.

**J:** There was that scatter-brained woman who used to spill her handbag all over the floor.

**L:** Yes, she was good. She seemed to understand Jim and understand us I think. You got to know her well ... When you have lots of social workers, every time they come it's a formal meeting, you are repeating yourself, and other times they ask you the same ...

**J:** You fill out the same form, you say the same thing.

**L:** And then you take Jim off to the centre so that they can meet him and they say, "We've seen Jim now, okay," and tick a box. But she always sat with Jim.

**J:** She interacted with him.

Justin and Lucinda describe the difficulties in obtaining respite care.

**J:** One of the issues was the fact that there was a lot of change in staff. There wouldn't be the same people there every time you went in and so therefore there was not always the understanding of his particular needs that perhaps there should have been. There were issues about if he was poorly, he would be immediately hospitalised, even if we were away on holiday, and then some member of staff would have to go with him and then they couldn't stay, as they were short of staff. I worried ... Rosemary [Jim's sister] had helped out quite a bit in that respect but obviously she has her own children and she's got her own job and so on, she works. On one occasion they insisted ... I had to fly back from Ibiza, was it? I had to go and sit with him in hospital for three days and then when it looked as though he was recovered I went back out. Now, that wasn't an issue as I was probably the best person to be with him and help him, in terms of the fact when he once started to take fluids he perked up a lot. But they said: "... well, it's not our job. If people are ill it's not our job to look after them ..." Well, what good is respite if you can't go on holiday? That wasn't the first time. We were constantly on edge and Lucinda would say to me, "Ring up and check he's all right." And I know damn well I'd get a phone call if he wasn't. You know,

really your whole life was dominated by caring anyway, and if the respite service couldn't provide you with respite if he was not feeling well, then it wasn't luxurious was it?

The other thing was that we had, through social services, arranged something called "adult placement". There was a guy who was really good about finding people who would take Jim over a weekend or a few days or just for one night or if something cropped up at short notice like you want to go to a funeral or something like that, he got somewhere where he could go. And then we went through one or two, lots of people, but it didn't last long, most of them. They found somebody in XXX and she was excellent. You had other adults there and it got very difficult because Jim would get up in the night and start wandering about and disturb the other service users and so on. She was brilliant. Then social services, they stopped ... they said they couldn't divide the respite care between two lots of services. So adult placement and the county council provided respite. I couldn't understand why somebody like the social worker couldn't monitor how many hours or days or whatever they had in the one place. And then the social worker said, "I shouldn't rock the boat if I was you as very few people get the amount of time that you get" – yes, quite. So it sort of petered out, didn't it, the placement?

There was no continuity of staff. There weren't always the same people around when Jim was there. We had issues about the levels of personal hygiene, as he always got sick when he came back from there. You know you've got people who don't understand personal hygiene being there with him.

**L:** You mean service users, not the staff.

**J:** Other service users, yeah, who didn't understand personal hygiene because they've all got learning difficulties and so very often he would get sick or soon after he came back from there.

Justin and Lucinda talk about Jim's behavioural issues and the impact on their own health of caring for Jim.

**J:** When he was younger it was quite difficult to go anywhere. You had to be very aware of what he was doing as he could lash out and smash ornaments and things like that. I think he broke two televisions in our house ... he used to have a TV in his room ... until I managed to get a means of screwing them to the wall. I think ... he has frustration, or perhaps not being able to express if he was in pain. But just general frustration at not being able to express himself. In terms of help with that, he was prescribed with ... what was that drug? It was a sedative-type



drug to calm him down anyway. We did try it. One tablet was far too much as it just knocked him out and then it broke his routine. It messed with his sleep pattern. And even half a tablet had an impact which we thought was undesirable. At one time we asked the doctor about sleeping pills and he said, “Well, they don’t really work unless you ... you have to know that you’ve taken them”, sort of thing. I don’t know, well, anyway. Usually the tablets went out of date before he ever took them. But they were there and they used to go with him to respite. I don’t know that they ever used them.

**L:** I don’t think they did. The pills just wiped him out. He’d be asleep for the next day, all day. It was horrible.

**J:** It was horrible. So rather than that, we just put up with him with it. He would pull people’s hair – quite often that was being over-affectionate rather than aggressive. That could be difficult, very challenging even for Lucinda and I. Or he’d pull my ears ...

**L:** He was scratching.

**J:** ... and not let go, or grab hold of his hair, really pull at it and not let go. Sometimes we had to restrain him, sometimes he would throw himself on the floor. We would say, “Well, you are going to have to go to your room, Jim,” and then he’d lie on the floor and refuse to get up. Then I’d have to manhandle him up the stairs. Obviously when you are getting older and he’s getting quite big, it’s challenging, something Lucinda couldn’t do.

**L:** He quite often would bite us, bite himself ... and the escorts in the taxi. We had to take his shoes off sometimes so he couldn’t throw his shoes.

**J:** Oh, yes, he’d throw his shoes from the back of the car into the front of the car.

**L:** He banged his head on the window of the car so they had to put him in the middle of the taxi so that he couldn’t reach.

*And did you ever get any advice or help and support about how to manage all of that apart from prescribing drugs or sedatives?*

**L:** I don’t think we were ever asked, were we?

**J:** I don’t know. I think anger-management therapy would be appropriate, really.

*Did the service offer any counselling, therapy support to either or both of you?*

**J:** Lucinda went to the doctor to get antidepressants, if that counts. She’s been on them for years.

*So how long ... if you don't mind my asking, how long have you been on them?*

**J:** Decades.

*When you were on antidepressants, presumably you were reviewed, did the health-care professional have any questions about why you were on them?*

**L:** I don't know if they asked. I kind of made an excuse for having them. So it was "I've got a full-time job" and ...

*And you are looking after Jim. Did they pick up on it at all?*

**L:** No, they just prescribed more.

*Did anybody ever ask you, apart from friends and family members, how are you and how are you coping?*

**J:** People would say, "We don't know how you are coping." [laughs]

Justin and Lucinda talk about Jim's death, aged 36.

**J:** The scenario was this, basically. We returned from Turkey. Jim had been in respite. When you are with somebody you don't notice how much change takes place on a day-to-day basis, it's very little but over a longer period it's marked. But his condition had worsened in terms of his inability to keep food down. I was always aware of the fact that there was a danger of somebody, particularly if they were asleep, ingesting their own vomit, so that was always an issue. Clearly, we didn't know at the time when he'd been in respite that he'd had had an incident or two of vomiting. Was that right, Lucinda, when he was in respite?

**L:** Yeah. Four o'clock he came back, he was with us on Tuesday night and we went to the centre on Wednesday and when he came back from the centre he was very [mimics Jim's breathing], wasn't he?

**J:** Yeah.

**L:** And he wouldn't eat his tea.

**J:** Anyway, he got up ...

**L:** After his bath.

**J:** ... walking along the landing, clearly struggling to breathe. He wanted to go into the bathroom and he collapsed on the floor and he stopped breathing and went blue, didn't he? And I gave him mouth-to-mouth, at which point he brought up some fluid and made a slight recovery but he was still struggling breathing. And I said to Lucinda, "Phone for

an ambulance.” In the past, we’ve got first responders and they’ve been really good and they would be out within ten minutes.

**L:** And quite often it’s someone who knows Jim, isn’t it?

**J:** Yeah, it was. Long-standing friends, actually, people who used to be in the same babysitting circles. They just don’t have the people anymore in first responders ... Somebody came eventually and shortly after that the ambulance arrived and they asked, you know, the type of questions they needed to ask and we answered them as best we could and I went with him in an ambulance. I sat in the front with the driver and the other ambulance staff were in the back with him. They gave him an oxygen mask.

We got to the hospital; we were taken into intensive care, I think. It might have been, I don’t think it was A&E. He was in a cubicle and was obviously in distress. They tried an oxygen mask on him but he wouldn’t keep it on and I had to hold it on. Then he vomited and he basically stopped struggling, he gave up. The consultant came and said, “Clearly he’s in a bad way,” and he said, “We could put him on life support but if I do that he’ll probably be on life support forever.” He said, “Really I think that ...” He gave the impression that he’d looked up something about Robinow syndrome, but obviously, as I said, Jim didn’t particularly conform to that and I knew the reason why he was struggling and what had happened. Because I said he’d probably swallowed some vomit or a lump and it’s gone down to his lungs and that was why he was struggling breathing. But, you know, I explored afterwards why he couldn’t do anything, like you do. And so I said to him, “Well, if that is the case, well, there’s no point in prolonging his life just for the sake of it,” which is a very difficult thing to say, isn’t it? So he said, “Go and hold his hand,” and that was it, really.

**J:** The issue afterwards was when we went to the registrar’s office to register the death, we’d been given an envelope and taken it to the registrar without looking at it. The cause of death was Robinow syndrome and we both were taken aback because we were just shocked that was the cause of death and we didn’t think it was the cause. Then I phoned the hospital and asked to speak to the consultant because I wanted to ask why he’d put that on the death certificate.

In the meantime, before I actually got to speak with him, we did a lot of research. And of course after thirty-six years there’s a lot of information available on the Internet about all sorts of things. And so we discovered that one of the things that with people with Robinow syndrome was that they had restricted orifices. I mean that was one of the reasons why ... because he used to suffer with constipation, for instance; why he couldn’t breathe. All those things must have been, in a way,

related to Robinow syndrome but unbeknown to us, because we thought his acid reflux and his other things, his digestive problems, were something separate. So when I spoke to the consultant and he explained why he put that on there and he said, if you want to go and see if the coroner will ask for a post mortem you can do that but bear in mind that will prolong things, maybe for weeks, before you can have a funeral, et cetera, et cetera. We discussed this and said, “No, we accept that decision now and we have a greater understanding about what his condition could involve.”

**L:** The registrar was excellent, wasn't she? She was very kind.

**J:** She said, if you are not happy with that, you go back to the hospital.

*And that's what you did?*

**J:** Yeah, straight back to the hospital and said we are not happy and we want to speak to the consultant. I spoke to him on the phone afterwards and he was very, very upset because you could tell that it had been ... it was a difficult decision for him to make as well.

*About whether it was correct to put the cause of death as Robinow syndrome?*

**J:** Yeah ... I mean, at the end of the day it doesn't make any difference, does it? We were only concerned that we thought it might reflect on anybody else who might have a child that's got Robinow syndrome, that they would get worried about things that might need not worry them at all. Because so many people with Robinow syndrome, all the other cases that we'd ever looked at, no child ever had learning difficulties. And the reason why we believe (and we didn't mention this earlier) he possibly could've had brain damage because they took some time to get him breathing when he was 4. So lack of oxygen could have caused brain damage. And there's no other documented case that we can find of anybody who had Robinow syndrome having learning difficulties.

**L:** Slow learners.

**J:** Not severe learning difficulties.

*So it was only after Jim's death that you went back onto the Internet and had a look at things. Do you think that was helpful in a way, not to track it closely over the years?*

**J:** I did try once. There was an organisation in America and I emailed them and I asked a question about whether or not any of their members

of their organisation had severe learning difficulties but I never got a reply.

*So, looking back, do you think it was helpful to you that you weren't aware of Jim's progressive physical decline?*

**J:** It wouldn't have made any difference. You have to deal with those things as and when they arise, don't you?

*And that last communication with that hospital consultant – that helped you?*

**J:** He said to me, I'm here if you ever want to discuss anything with me again ... you know, this was a personal thing, he didn't have to do that professionally, he'd done his job, hadn't he? You know, at the end of the day, everybody has to come to terms with death and there's always question marks afterwards, aren't there about things, but you think, oh well, if it's not that it's the other. It's pointless really, isn't it?

*After Jim died, did you have any contact with the GP surgery at all about Jim?*

**J:** They sent a letter of condolence.

*Did that feel right?*

**J:** I thought that was quite touching, wasn't it, I thought. Lucinda, didn't you?

**L:** Yeah. When I went to take Jim's medication back to the pharmacy, the pharmacist came out and gave me a hug. Another nurse came past and gave me a hug and actually we went to see a doctor afterwards and we had a double meeting, didn't we? Afterwards, the consultant said he was sorry about Jim.

**J:** You know, we've been with that practice for well over thirty years and obviously lots of things have changed in that time. But ... some of the GPs we don't know at all, but the people we've had contact with there have always been really helpful.

### *Story 5: Eve*

This is a story fragment about Eve who displayed symptoms of diabetes as a small child that were missed until the family moved home and registered with a new GP practice.

**Eve:** I was 10 ... It was my mum, really, that found out ... She kept taking me to the doctor, and I can remember one day in particular going out with the school and having to ask the teacher for a drink. For some bizarre reason that stays in my memory 'cause I was so, so thirsty when my sugar was high. Because I was an only child I think everyone was treating my mum as if she was a kind of neurotic mum, and they kept saying, no, there's nothing wrong, no, there's nothing wrong. And we were living in Huntingdon at the time, and then it was when we moved to London that we went ... I think we went to a doctor's about something else, and he said, how long has she been diabetic? And my mum said, what do you mean, diabetic? And I was then sent straight along to the hospital.

### *Story 6: Finbar and Eileen*

Eileen's son, Finbar, has scoliosis, which is curvature of the spine. It is usually painful and becomes more noticeable as the child grows. When serious the condition can only be treated by having a complicated operation in a specialist unit. Eileen has found the long wait stressful and has had to chivy the NHS along to get an appointment with the spinal specialist. The support group that she joined was helpful. A physiotherapist spotted that Finbar might also have Marfan syndrome; this wasn't picked up by the other specialists.

*So how old is Finbar now?*

**Eileen:** Sixteen. He's been diagnosed with scoliosis, which is curvature of the spine, which I noticed last August when we were on holiday. He's been to see the GP and then he's been referred to the spinal specialist at XXX for fusion surgery.

When we went to the GP, she had a look at him, confirmed that, yes, she thought it was scoliosis, and then the next stage is then to refer him to the paediatric consultant at the local hospital. So we saw the GP in August and we eventually got an appointment in December to see the paediatric consultant.

*Did that feel like a long wait?*

**E:** That was a long wait and it was like a self-booking system, so there were two hospitals that we could pick from and I wanted to pick XXX hospital, and when I went onto the system there were no appointments

loaded up on there, so I had to ring through and they said there weren't any appointments at the moment, they were waiting to get some appointments created and then as soon as they were they'd send me a letter through with an appointment date.

I knew it was scoliosis, I could tell from what I'd looked at online, she sort of confirmed it but she said the next stage then was to see a specialist to see what they could do then, but she did the standard test what they do, where they have to bend over to see whether, you know, they can see like a hump on their back and things like that, so yeah. But they're not the experts in it so I knew we'd have to get referred.

So we went to see the paediatric consultant in December who had a look at him, did some tests on him, his reflexes and things like that, confirmed that, yes, it was scoliosis and that he would then need to be referred to a spinal specialist and they would refer him to XXX. In the meantime he had an X-ray, and they said, yes, he's got a curve, they couldn't say how many degrees it was, they said that would be for the spinal specialist to confirm, and they said he would also have an MRI scan. So they referred him to XXX and then we had an MRI scan in December and then we got an appointment through for XXX for April this year, which I felt was quite a long wait ... yeah, so it's August 2018, we then saw the consultant in December 2018, and finally got an appointment at the spinal specialist in April 2019.

*Is scoliosis one of those conditions where as soon as it's been diagnosed, treatment earlier rather than later is a good idea ... ?*

**E:** It depends how severe the curve is, because they say if your curve is more than 50 degrees, then it's classed as serious, and normally then you would probably have to have surgery. If it's less than 50 degrees, they can monitor it more and you can have a brace and that can be more monitored, but once it gets to over 50, they say that you would probably be better off having the surgery to correct the curve. It can be painful and obviously it's ... because he's at that age like 16, it's like image, so he's twisted and ... his shoulder blade sticks out on one side.

When he has clothes on, you can see his back that his shoulder blade sticks out and he has a little bit of what they call a rib hump at the back where it's pushing towards one side because the spine is curving. And you normally notice it when they're teenagers because it's when they have a big growing spurt.

The type that he's got is adolescent idiopathic scoliosis, which means that they don't know why they get it, but it's just common in teenagers,

normally girls more than boys, and that they don't really know why but that's when it's noticed with a growing spurt.

The pain's got gradually worse because his curve has got gradually worse, so at the moment ... he says he's really uncomfortable after he's been sat down for quite a while because he can't rest his back against a chair properly because his back's not straight. And then also when he does sport and things, after a while it can hurt but he plays badminton and the doctors and that said you've got to just carry on as normal with everything because it's not weak or anything, your spine, it's just that it's disfigured.

So he does still carry on and they say that's the best thing, to carry on as normal and do everything that you normally can. And he went away to space school in the summer and he was doing things like scuba diving and indoor flying and he said that that did cause a few problems with his back and he was really sore. So it's limiting of things now ...

He's also been under the physiotherapist because he was having pain and they're trying to get his core muscles strong for when he has the operation, and the physiotherapist noticed that he's got very thin and quite long limbs and fingers and high arches in his feet and she wondered whether he might have some genetic problem like Marfan syndrome. So we're also linked to this, we're also going to see the genetics clinic in XXX in December to see about that and he might have to have a blood test and have some genetic testing, and if he has got something like that, then scoliosis actually is a link with Marfan syndrome, so we're not really sure yet.

For the scoliosis it's been a long delay, I think. It's the fact that having to go to the consultant and then they then have to refer you, I don't understand why the GP couldn't have referred us directly to XXX, to the spinal specialist. I'm on a forum with other people whose children have got scoliosis, so I knew that this was the process and a lot of people said it takes such a long time and it's so frustrating, because you know that they've got it, but it just takes all that time to actually get a confirmed diagnosis, and it's that in between stage.

I'd read that people say that's just the way it is and I did ring the specialist and see whether there were any earlier appointments or anything like that but that was the earliest appointment that they had on the system, so I got the appointment through in January for April.

Finbar's all right about it at the moment, I think because he's now seen the consultant and he's explained everything, and because he knows that something is going to be done. He's going to have fusion surgery on his back where they put rods in his back to straighten his spine, so it's quite major surgery.



When we first went to the specialist, they said roughly around twelve months' waiting list, so we knew it was then going to be another twelve months before he actually had the operation, so that was April, and I got an email from them this week to say that they'd looked at the list and they can probably do his operation in January/February next year [2020].

I think he was classed as a severe case, so he was on the urgent list, which is six to nine months.

*So how do you feel about how the care has been organised for Finbar, so far?*

**E:** The care is good, it's just the wait, it's just such a long wait for things like that, and to see him in pain ... you just want it done as soon as possible. It feels like it's just such a long time from us knowing and seeing the GP to actually seeing somebody, and then even a further twelve months to actually get the operation. But the care has been good, it's just the slow process ...

*Can I ask you, because you're obviously very informed and you know how to get the system to work for you, how many times do you think you've got involved to speed things up?*

**E:** So for the initial one with the paediatrician, I probably had to contact them about three or four times because they didn't have any appointments so I kept ringing to see whether any had been added to the list.

*And do you think that as a result of that, you managed to get Finbar slotted in a bit earlier than might otherwise have happened?*

**E:** I don't know really, because every time they just said no, there weren't any appointments and you'll get an appointment through, so they wouldn't actually give me one over the telephone, so I still had to have something sent through the mail. And then the one for the spinal surgeon came through fairly soon, I just thought, well, I'm not going to change that one, I'm just going to have to keep that, I rang up once to see whether we could get anything any sooner and she said, I'll take your details if there's any cancellation, but there wasn't any. And then it's probably now that I'm chasing more because I'm wanting to see where he is on the list ... I did chase quite a few times for the results of his X-ray, so he had his X-ray in August and I didn't get an update until October, and I think I rang four times ...

It's frustrating and worrying as well, because you just want everything to be sorted, and the operation to be done and then you can move on. And especially when you see your child when they're in pain.

I rang the GP because he was getting a little bit of pain and that's when they then referred him for physiotherapy.

*Has the physio been helpful?*

**E:** Yeah, very helpful, and the physiotherapist was really good because she's the one who's actually noticed the other things regarding like the genetic side of it, so it was her; nobody else had said anything about that ...

Years ago when he was about 8 years old – well, no, when he was born – he had problems weight bearing, so he had to go and see the specialist in XXX when he was about 2 years old because he wouldn't weight bear, and they said he had high arches in his feet so he had some shoes made and then he could walk. And we were under the specialist for about a year and then they said, he's fine now, there's no problems, what will happen is probably when he's about a teenager he might just get some aches in his feet, so we never thought anything of it. And when he was about 8 or 9 I noticed that he couldn't straighten his fingers, they're like a little bit bent and they can't straighten them fully, so we went to see the doctor and the GP just said, everything's fine, there's not really a problem unless ... she said something like, unless he wanted to be a piano player, then everything will be fine. So looking back now, there obviously was something but nobody like linked it or picked it up and it's only because he's a teenager now.

Marfan syndrome is a genetic syndrome that affects some connective tissue, and usually they're quite tall, very thin, got long fingers ... their arm span, if they put their arms out, their arm span is longer than their height ... so he has quite long arms. He has said people at school have commented about it and he always says my hands look funny, and he has got really long fingers, but I just thought that was his build and he's a teenager so they're growing, they are skinny and things like that. And because I knew about his feet and things but just thought, well, there's nothing, you know, everybody's said he'll be fine, but actually now ... they might not be, but ...

It's like a long-term condition, they say that it can affect your heart, your aorta can become enlarged or something, so you would have to have regular ECGs and things like that, so that's the bit that I'm concerned about with that side. And that obviously was only picked up with the physiotherapist, that wasn't picked up with the spinal surgeon, with

the paediatrician, with the GP, nobody picked that up at all, it was the physiotherapist that pushed to get him referred. So she referred him back to the GP and the GP contacted me and said, it could be Marfan, so I will arrange for him to be tested.

The physiotherapist is really good and she's been really accommodating with appointments. And she also referred him to get some insoles with his feet as well, so the orthotist. So there's been quite a few things that have gone on with him and it's all happened at this age.

Eileen goes on to talk about how helpful it's been to be part of an online support group:

**E:** It's a Facebook group that I found that is a closed group for parents whose children have got scoliosis, and that has been the best information, and I do put a few posts on and get responses from people who are all in the same situation, that's the people that say, keep chasing, do this, do that, you'll be waiting twelve months, it is a slow process. So it was all people with past experience that has helped more than the actual system.

### CHILD HEALTH: REFLECTIONS AND RESPONSES TO THESE STORIES

#### Immediate questions

1. What examples of kindness and compassion – or the opposite – particularly struck you in these stories? How did they make you feel?
2. What do these stories tell us about communicating complex information to parents? How to judge what is the right amount?
3. Why did the cause of Jim's death matter?
4. Is it important for patients and families to know "who is in charge" in a hospital setting? How is this best communicated?
5. Are healthcare professionals aware of what annoys and alarms patients and parents in a hospital setting?

#### Strategic questions

1. How can personalised and age-appropriate care be designed into services?
2. Why is continuity of care so important for children and their families?

3. What can be done to speed up processes of diagnosis and treatment, for example looking at Finbar's story as told by his mother Eileen?
4. What responsibilities does the NHS have to ensure a joined-up service for young people who also need support from social and educational services? How can these responsibilities be met at different levels?
5. What are the NHS's responsibilities in relation to the physical and emotional needs of parents? How can they be met?
6. How might COVID-19 have affected non-COVID care for better or worse in Dan's case? Are there longer-term implications for the design and delivery of services?

## REFERENCES

- Bryar, R.M., S.A. Cowley, C.M. Adams, S. Kendall and N. Mathers (2017) "Health visiting in primary care in England: a crisis waiting to happen?" *British Journal of General Practice* 67 (656): 102–103.
- Colver, A., T. Rapley, J.R. Parr, H. McConachie, G. Dovey-Pearce, A. Le Couteur et al. (2019) "Facilitating the transition of young people with long-term conditions through health services from childhood to adulthood: the Transition research programme", *Programme Grants for Applied Research* 7 (4), [www.journalslibrary.nihr.ac.uk/pgfar/pgfar07040#](http://www.journalslibrary.nihr.ac.uk/pgfar/pgfar07040#) (accessed 4 January 2021).
- Council for Disabled Children (2019) "It takes leaders to break down siloes: CDC's new report on integrating services for disabled children", <https://councilfordisabledchildren.org.uk/help-resources/resources/it-takes-leaders-break-down-siloes-cdcs-new-report-integrating-services> (accessed 4 January 2021).
- King's Fund (2017) "What policies are needed to improve children's health?" 30 May, [www.kingsfund.org.uk/publications/articles/big-election-questions-children-health](http://www.kingsfund.org.uk/publications/articles/big-election-questions-children-health) (accessed 18 December 2020).
- NHS (2019) *The NHS Long Term Plan*, Version 1.2 with corrections, August, [www.longtermplan.nhs.uk/wp-content/uploads/2019/08/nhs-long-term-plan-version-1.2.pdf](http://www.longtermplan.nhs.uk/wp-content/uploads/2019/08/nhs-long-term-plan-version-1.2.pdf) (accessed 3 January 2021).
- Public Health England (2018) "Health profile for England 2018", research and analysis, 11 September, [www.gov.uk/government/publications/health-profile-for-england-2018](http://www.gov.uk/government/publications/health-profile-for-england-2018) (accessed 3 January 2021).

Royal College of Paediatrics and Child Health (2019) *State of Child Health in the UK* (London: RCPCH).

Smith, J., F. Cheater and H. Bekker (2015) "Parents' experiences of living with a child with a long-term condition: a rapid structured review of the literature", *Health Expect* 18 (4): 452–474.

WHO (2008) *World Health Report 2008 Primary Health Care: Now more than ever* (Geneva: WHO) <https://who.int/whr/2008/en/> (accessed 29 December 2020).