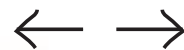
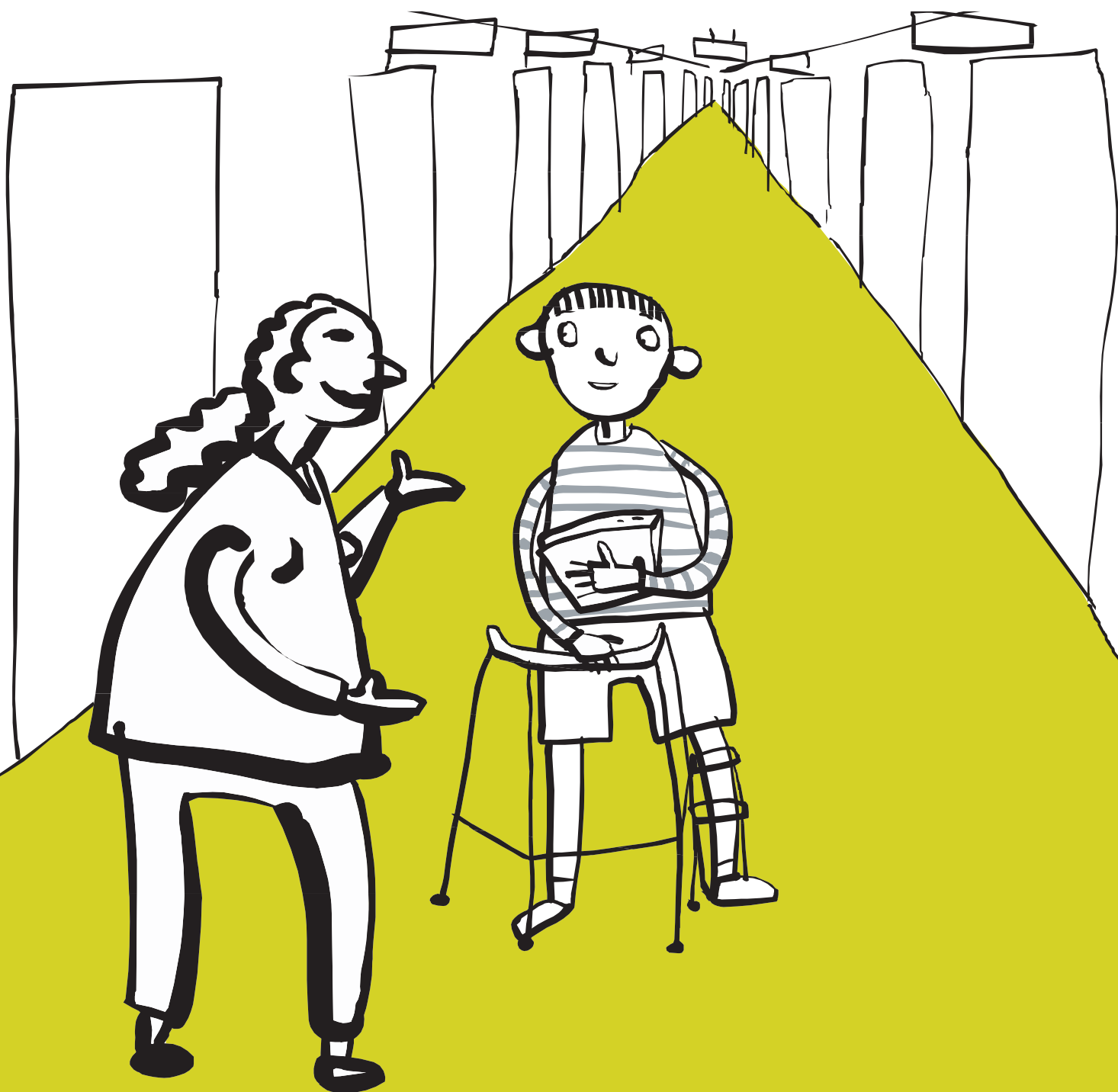


It's managing MY way  
and how I want to live MY life  
it's not only doctor's appointments  
and controlling my condition

It's about how I can live with  
my condition but still have  
a good time and just be  
a young person



# managing MY way





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This report can be downloaded from [www.councilfordisabledchildren.org.uk](http://www.councilfordisabledchildren.org.uk) where you will also find downloads or links to other helpful resources.

The Council for Disabled Children (CDC) is the umbrella body for the disabled children's sector in England, with links to the other UK nations. CDC works to influence national policy that impacts upon disabled children and children with special educational needs and their families.

CDC's broad based membership and extensive networks of contacts provides a unique overview of current issues. It also enables us to promote collaborative and partnership working among organisations.

CDC's vision is a society in which disabled children's life chances are assured, their needs are met, their aspirations supported and their rights respected.

CDC hosts the following networks;

- ◆ The National Parent Partnership Network
- ◆ The Special Educational Consortium
- ◆ The Transition Information Network
- ◆ Making Ourselves Heard

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# Introduction

Despite the fact that disabled young people are disproportionate users of health services, there is very limited evidence of any systemic practice of involving them in planning and managing their own healthcare.

This report seeks to begin to address this gap. It documents current policy and published research evidence regarding the involvement of disabled children and young people. The report outlines the experiences and views of 41 young people and 39 healthcare professionals obtained through focus groups. It details the barriers and challenges faced when supporting disabled young people with long-term health conditions. It then goes on to outline some of the solutions to helping them to manage their conditions more independently and to be more involved in decisions about their healthcare.

Two key overarching themes emerged as a result of these discussions: the importance of getting interactions and relationships between professionals and young people right; and the importance of developing young people's ability, confidence and independence around managing their own care. Working in partnership with disabled children and young people was identified as critical to fostering compliance with treatment programmes. Supporting independence from the earliest age was identified as a vital foundation for favourable transition to adult services and adult life.

The report highlights a number of recommendations, both at the structural and individual level, designed to improve young people's experience of and participation in their healthcare.



# Policy context

This section outlines the legislative and policy framework as well as reviewing the research literature in the areas of participation, self-directed care and personalisation. It ends by examining some of the barriers that may at times prevent legislation and policy being implemented as intended.

## Participation

Since the 1990s the UK government has expressed a strong commitment to supporting the rights of children and young people, including those with disabilities, to express their views on all matters affecting them. Legislation and policy across health, education and social services has been introduced with the intention of helping disabled children and young people to become as self-reliant as possible and promoting their consultation and active involvement in shaping the support services they receive (Franklin 2008; Townsley, Abbott and Watson 2004; Stone 2001). The *Children Act 1989* and *2004*, the *Human Rights Act 1998*, *Disability Discrimination Act 2005*, *UN Convention on the Rights of the Child 1989* and *Convention on the Rights of Persons with Disabilities 2006* (to both of which the UK is a signatory), all declare a strong commitment to promoting the autonomy of disabled people and their full participation in society.

The Department of Health made a commitment in its publication, *Valuing People: A new strategy for learning disability for the 21st century (2001b)*, to providing services that improved advocacy and to providing information in accessible formats to give people with learning disabilities more choice and control in their lives. The *National Service Framework for Children, Young People and Maternity Services* (Department of Health 2004a) stated that disabled children want carers to listen to them, ask them for ideas, take notice of what they say and give them choices; and that professionals should therefore work to:

*... ensure that disabled children, especially children with high communication needs, are not excluded from the decision-making process. In particular, professionals should consider the needs of children who rely on communication equipment or who use non-verbal communication such as sign language.*  
**(Department of Health 2004a)**

Such a commitment was reiterated in more recent policy documents, such as *Aiming High for Disabled Children: Better support for families* (HM Treasury and Department for Education and Skills 2007). Specific good practice guidance on transition – given in *Transition: Moving on well* (Department of Health 2008b) and *A Transition Guide for All Services: Key information for professionals about the transition process for disabled young people* (Department of Health 2007) – makes it clear that there is an expectation that professionals should be facilitating increasing autonomy amongst young disabled people, for example in the early stages of formulating a transition healthcare plan.

*The young person should become aware of their own health and care needs, and the full implications of their medical condition ... The concept of seeing a professional on their own should be gradually introduced to the young person in order to give them and their family time to adjust to this change.*  
**(Department of Health 2007)**

Whilst for some young people the likely need for continuing support by carers, as well as services, is recognised, the guidance also makes clear that it is important that children and young people are spoken to separately and for them 'to have a voice that is separate from that of their family' (Department of Health 2007). Russell

(1995) confirms the importance of allowing the disabled child the opportunity to speak openly of their concerns and to ask questions about their condition – even where this may be uncomfortable to protective parents who may, for the best of motives, try to restrict or censor information that they think will be distressing.

*The opportunity to discuss his condition quickly revealed that John did have an idea of his medical prognosis. Indeed, unable to ask anyone and anxious not to upset his parents, he feared he would die in his sleep and was very depressed.*

**(Russell 1995)**

## Self-directed care

The White Paper, *Our Health, Our Care, Our Say* (Department of Health 2006a), set out the previous government's vision for community health services. It was premised on the principles of 'giving people more choice and control over their care services'; that each individual has, and also wants, responsibility for maintaining their own health; and that where people are involved in choosing services and making decisions about the kind of treatment and care they receive, the outcomes are likely to be better. It committed the government to providing advice, support and information (in the case of disabled children, this was to be especially at critical points such as transition to adult services) but also envisaged individuals taking more personal responsibility and exercising positive health choices.

There is now considerable literature on the professed benefits of increasing self-care/ self-management of conditions. The benefits outlined are: increasing individual autonomy and responding to the preference of most people for partnership in healthcare; reducing demands on the NHS and holding down the burgeoning costs of healthcare; and technological advances that enable more care to be safely provided at home (Ryan and others 2006). Ryan argues that there is a need for partnership between professionals and patients to ensure that the public have enough confidence and information to make

informed choices about when and how to care for themselves and when to call in professional help. *Saving Lives: Our healthier nation* introduced the concept of the 'expert patient' (Department of Health 1999). It describes a programme intended to produce these expert patients, that is, patients who are better able to manage their own health conditions. They would be enabled to help themselves by adopting positive life-styles and health-promoting behaviours, using their medication correctly, and recognising and acting appropriately to symptoms. Though at first it was aimed primarily at promoting increased self-management for people in later life, *Saving Lives* made it clear that it could also be applied to children. This is confirmed in the *National Service Framework for Children, Young People and Maternity Services*:

*As well as contributing to family support packages of care, the NHS Expert Patient Programme has great potential for increasing the quality of life for disabled children who have health needs. Parents or carers, children and young people can benefit from becoming experts in the child or young person's specific condition.*

**(Department of Health 2004)**

Literature suggests that well-informed and supported children and young people can and do take personal responsibility for helping to manage their health and serious medical conditions from a very early age, including conditions such as diabetes, asthma, cystic fibrosis and spina bifida. Apart from any direct health benefits resulting for the individuals, it can increase their wider sense of self-efficacy and control over their lives and futures, Alderson and others 2006, Robinson and others 1985, Parrish and others 1989, Butz and others 2007, Guevara and others 2003, and Wasilewski and others 1996).

*Staying Positive* was the title given to a series of workshops run – under *The Expert Patient* programme (Department of Health 2001a) over a period of six weeks – for young people aged 12-18 who are living with a long-term health condition. The workshops aimed to give them the skills to improve their self-management skills in relation to their conditions, both from a health

perspective and in terms of leading as fulfilling and independent a life as possible. The programme for the workshops was developed from direct consultation with young people who were asked what the content and format of the events should be. The seminars were facilitated by young people who were themselves living with a long-term health condition, supported by a trained adult as necessary. Workshops covered topics such as communication with family, friends and healthcare professionals; social life and friendships; medication adherence; feelings; independence and transition; and sex and drugs.

*The peak time for decline in self-management skills is in early adolescence, when young people in the search for independence begin to reject adult supervision of their condition. At the same time, research shows that once problems of self-management become established they become difficult to rectify.*  
**(Staying Positive, a self-management workshops flyer, 2007)**

The evaluation of the Staying Positive pilot workshops found that young people enjoyed taking part; and their involvement helped them to learn more about their conditions and how to manage their health better. This underlined the importance of medication adherence, but in ways that helped the young people adopt a more positive attitude to something previously seen as burdensome. Young people said participation had boosted their confidence both in managing their condition and in general. It had helped them to understand the importance of talking directly to doctors and nurses rather than relying on their parents to do it for them, and had helped them to do so more effectively. After participating in the workshops, young people who were more involved in their self-care reported that their parents seemed more confident and trusting of them to manage their health than before and 'less uptight about letting them go out or being a bit more independent' (Salinas 2007).

Recent research carried out by the University of Manchester (Kirk and others 2010), which reviewed a number of evaluations of self-care support for children and young people with long-

term conditions, reached similar conclusions. A number of the evaluations reviewed had reported statistically significant relationships between group-based approaches and improvements in health status, self-management and reductions in feelings of loneliness; and improved communication skills with professionals and parents.

*Getting the Right Start: National service framework for children – emerging findings* (Department of Health 2003) acknowledged the risks necessarily taken in facilitating autonomy in matters of health and medication adherence. It accepts, for example, that children and young people may sometimes 'find it difficult to take their medicines as prescribed'. Nonetheless, it says that involving parents, carers and children in decisions about their medicines, and then supporting them in taking them effectively, could have considerable benefits for improving their health – especially as young people move towards adulthood and, inevitably for most, greater independence. Again, this finding is supported by the Manchester University study (Kirk and others 2010), which had found a number of evaluations that highlighted the importance of parents having an ongoing role in order to minimise the deterioration in health status which is sometimes observed during adolescence.

The White Paper, *Equity and Excellence: Liberating the NHS* (2010), continues this trend, emphasising the critical importance of patients being fully involved in decisions regarding their care and treatment – 'no decision about me without me'. However, there are concerns about whether or not sufficient thought has been given to making this real for disabled children and young people. Concerns also remain as to whether the wealth of other legislation and policy – affirming the rights of disabled children to be heard and to be facilitated in becoming as independent agents as possible in their lives, including their healthcare – will be realised.

*Evidence from Quality Protects and elsewhere suggests that, while in general children are increasingly involved in decision-making, growth has been slower in respect of involving disabled children directly.*  
**(Franklin and Sloper 2007)**



## Personalisation

Participation in decision-making regarding healthcare may be propelled into another league by the increasing move towards personalisation.

The concept and practice of personalisation of care has been evolving over some time. The government is committed to continuing and extending work in this area. Debate still exists about how far services should be personalised, but it is largely agreed that this agenda provides a positive way forward both for providers and consumers. A large part of this agenda has seen the spread of the use of direct payments and individual budgets: giving service users control of their budget and enabling them to purchase services from their choice of provider.

'Personalisation' seeks to prioritise user 'choice and voice', aiming to involve participants in the design and delivery of public services. In the UK, the personalisation agenda is furthest advanced in adult social care, where individualised case planning, direct payments and individual budgets are already being mainstreamed, radically changing the way that many services are provided.

The personalisation agenda is moving rapidly and is actively supported by all major political parties on account of the benefits offered in terms of choice, independence and cost effectiveness. However, the potential benefits – and risks – will differ depending on a range of circumstances that include needs, professional expertise, support networks from family and friends, and what options are available.

The introduction of direct payments and other models of self-directed support and personalisation, such as individual budgets, have been seen as key to delivering people greater 'choice and control' of services (social care and health); and thereby to improving the user's subjective experience, their independence and sense of personal well-being, and also the objective quality of their care.

Personalisation – the shaping of services around the individual needs and wishes of patients, users of services or their carers – has increasingly become a central tenet of health policy. The Department of Health, in its publication *NHS*

*Next Stage Review: Our vision for primary and community care* (2008a), proposed the offer of a personal health budget to people with 'predictable long-term conditions'. The aim of the budgets is to give patients greater control over the choice and design of services which they receive and over who provides them.

There is every indication that this push towards personalisation will continue. The Department of Health's Individual Budgets pilot programme is being continued. Twenty of the pilot sites have been selected for an in-depth study as part of a wider evaluation exploring the potential of personal health budgets to benefit different groups of people.

### Concerns and reservations about personalisation

The prime motive forces for personalisation and individual budgets are repeatedly given as innovation, individuation, transparency and cultural change. The concerns of some – that there may be hidden agendas more concerned with capping or reducing care entitlement – are denied by governments of all hues, though there is acknowledgement from all concerned that such measures will encourage more realistic expectation as to the funding available and will not prove *more* expensive than current structures.

Despite the theoretical benefits of increased personalisation there are quite serious concerns and reservations at this stage as to the possible implications of such a policy in practice. The publication *Evaluation of the Individual Budgets Pilot Programme: Final report* (Glendinning and others 2008), whilst noting the very real advantages of individual budgets in terms of flexibility – for example, being able to choose one's carer and develop a regular relationship with them thereby prioritising one's own needs – also identified anxieties and concerns amongst some recipients of services.

The evaluation found that, whilst individual budgets were relatively popular with people with physical and sensory impairments, people with learning disabilities and their carers could find the attendant processes and bureaucracy stressful. Individual budgets seemed most suited to the most competent and articulate. There

were also some concerns as to inappropriate use of budgets and, perhaps more worryingly, about safeguarding and monitoring issues and the possible exploitation of vulnerable people. Other evaluations (Prabhakar and others 2008) have found that some parents and young people experienced difficulties in coping with the new role of being an employer; with the financial management and administration of the budget; and in finding good quality personal assistants and care workers.

Bartlett (2009), writing in *At Your Service: Navigating the future market in health and social care*, concludes that at the moment personal budgets are working well for the relatively small number of people who are using them. For these people, such budgets do give them more control than previously over the shape of the services they get and the freedom to personalise them to their specific wishes, needs and lifestyle choices. For others, the innovation may hold less attraction:

*There will be a large group of people who want real change in what they use, and to chart their own course ... At the same time there will be many people who do not want to take on personal budgets, or at least want varying levels of control and responsibility, which could even change year on year.*  
**(Bartlett 2009)**

Regardless of such concerns the drive towards personalisation continues and it is therefore to be hoped that it will help, more than current processes do, to put disabled young people in the driving seat, as far as is possible, in decisions about their health and care.

## Barriers and aids to increased participation

In *Getting it Right: Involving disabled children in assessment, planning and review processes*, Marchant and Jones argue that often the barriers to involvement are located not in the individual, the 'problem' of the disability, but rather in the values and views of a society which sees childhood impairment as deeply problematic (2003, p.6).

Perceptions of competence and incompetence; the insuperability of communication difficulties; and overprotective attitudes, may distort objective judgements of what is and what is not possible. In terms of the negative impacts of social attitudes, several pieces of research indicate that low expectations, especially of disabled children who use methods other than speech to communicate, may be the critical limiting force. A focus on the child's incapacities, rather than capacities, can be the self-fulfilling predictor of what is possible (Russell 2003, Rabiee and others 2005, and Thomas and O'Kane 1999).

One of the underlying difficulties may be that the concept of participation itself has not been sufficiently broken down, or broken down in the right way, and therefore professionals may not see the possibility of participation from young people with more complex disabilities.

Carlin (2009) points out that most of the models used to explain participation are hierarchical in nature and are based on 'the ladder of participation' developed by Arnstein in 1969 to explain participation in community development. The different levels of participation, or the amount of participatory activity, range from simply 'taking part, being present, being involved or consulted' through to 'a transfer of power so that participants' views have influence on decisions' (Franklin and Sloper, 2007, p.6).

Although some theorists have developed non-hierarchical models of participation (for example, Kirby and others 2003, Tresesder 1997), which recognise that it is not always appropriate for children to have control or power in decision-making processes; others have retained the hierarchy in their adaptations (Shier 2001, Thoburn and others 1995). Thus, arguably, there remains a strong legacy from the hierarchical model's assumption that the highest level (citizen control) is the 'gold standard' or the ideal that all participation should aim for.

This idea creates unnecessary barriers when considering the participation of disabled children and young people in their healthcare. For some disabled children, taking control over their healthcare is utterly attainable. However, there are large numbers of disabled children who will not have the capacity to control their healthcare and

it is vital that because of that they are not denied the opportunity to participate at the level at which they are able. Carlin (2009) points out that children may participate by:

- ◆ being informed/having information
- ◆ expressing a view (this may be done by a third party on behalf of the child)
- ◆ influencing a decision/taking part in meetings and discussions
- ◆ being the main decider/giving consent.

All four ways are equally valid and no one level should be given greater status in determining whether or not disabled children are 'participating' in their healthcare.

There is significant commitment within the medical profession itself to the principles of participation. A decade ago the British Medical Association, in *Consent, Rights and Choices in Health Care for Children and Young People (2001)*, affirmed the ethical importance of respecting autonomy and self-determination; and drew attention to the rights of children with disabilities to assistance in order to achieve social integration and individual development.

In 2010, the Royal College of Paediatrics and Child Health published *Not Just a Phase: A guide to the participation of children and young people in health services*. The document concludes that:

*Children and young people have a right to participate in matters concerning them and as healthcare professionals we have a special obligation to ensure they have a voice, and that their voice is listened to. It is our responsibility to ensure children and young people are not only seen as beneficiaries but as key stakeholders of their health service.*

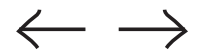
There are also more pragmatic reasons for participation:

*It makes health services better, it improves the health of children and young people and it's fun!*  
**(Royal College of Paediatrics and Child Health 2010)**

The principle of young people's involvement and partnership in healthcare decisions and services is mandated by government and professional policy. There are tools and resources which make that involvement possible and practical. However, it is clear from the young people and professionals we interviewed for our report that putting the principles into practice is still very much 'best practice' rather than matter of course.

We hope that by highlighting current progress and clearly highlighting the obstacles and the good practice that is happening, our report will help to move the concept of self-care for disabled young people on significantly.

# Findings



*It's managing my way ... this is how I want to live my life ... it's not only doctors' appointments, it's not only how I can control my condition .... It's about how I can live with my condition but still have a good time and just be a young person.*

Twelve focus groups were held in order to inform this report: seven with professionals and five with young people. The young people were aged from 15 to 21 and had a range of disabilities and health conditions. The focus groups with professionals were set up through contact with Primary Care Trusts. They involved staff from a number of disciplines and services including transition, education and social care. Commissioners, heads of service and front-line children's community nurses took part and we were therefore able to gain a comprehensive range of perspectives.

The focus for the professionals' discussions were the barriers and challenges to supporting disabled young people with long-term health conditions to manage their condition more independently and to be more involved in decisions about their healthcare. Professionals were also asked to comment on things that they thought worked particularly well in giving more control to young people. With the young people, the questions focused around who delivered healthcare to them, what their experience of that healthcare was like, what they might like to see done differently and how they thought that could happen.

Two key overarching and related themes emerged as a result of these discussions: the importance of getting interactions and relationships between professionals and young people right; and the importance of developing young people's ability, confidence and independence around managing their own care.

The following section will look in more detail at these two themes under a number of subsections. It will also examine tools and approaches which foster self-directed care.

## Relationships and communication with professionals

### Lack of continuity with healthcare professionals

A lack of continuity with one person and seeing numerous different healthcare professionals was a common concern amongst young people. Many reported seeing different doctors each time they had an appointment. This resulted in frustration, anxiety and concerns for young people as they had to repeat their history each time, which impacted on the time available to discuss their concerns and on their confidence – many reported that if they could see the same doctor, and develop a relationship whereby the doctor knew how to communicate with them and understand their needs, then they would feel able to visit them independently.

*It's a bit annoying. You end up telling loads of people, different people the same thing. So if they just gave you the same one you wouldn't have to repeat yourself.*

*Say you only have 5 minutes, you have to tell them your history ... you're feeling rushed ... then you're like 'I've only got 1 minute left to tell you all of it?' ... and then time is up.*

*Yeah feel messed about. Just get to know her and then she goes and I have to get used to another one, then they go and I have to start with my health ... re-say it.*

*Just one doctor ... I just want one doctor.  
No changing.*

*... [makes me feel] uptight.*

*... [if I could see the same person] Then I  
could just go in there and talk.*

Young people told us that although the doctor might know about their condition, they wouldn't know the nuances of how the young person was affected by that condition: their individual history, and their treatment preferences.

*Most of the doctors know about my  
condition, but obviously most of them don't  
know my background so I have to keep  
telling them that.*

*err ... sometimes it would be nice if there  
was a doctor who knew me for a while so he  
would understand me ... and also they would  
know my past history ... and understand  
what affects me and what doesn't.*

Young people felt that there was a knock-on effect of lack of continuity; that professionals couldn't see their development or encourage them to take more control of their treatment or support as they developed and matured.

In addition, many disabled young people had multiple professionals in their lives. Many young people found that this made it difficult to develop relationships with them, remember their different roles, and thus know who to ask for what support; and it made it difficult to navigate the system without significant support, which again impacted on their ability to increase their independence.

### **Developing relationships**

Being able to develop relationships with professionals was one of the most important aspects identified by all young people. They felt that this would enable them to develop a relationship of trust, which would then facilitate communication and make them more confident about asking questions. In addition, they felt

that this would mean professionals would get to know them as a person, rather than just a 'condition', 'symptom' or 'problem to be fixed'. This impacted on their experiences of accessing healthcare and, in particular, their confidence and ability to develop their independence and visit professionals on their own.

*... because when people get to know me they  
treat me like a human being, like including  
doctors who talk to me ... understand me.*

*All the time, all they've got is notes on the  
computer and when you walk in they seem  
to know everything about you ... without  
even knowing you. You are notes. You're a  
condition or a list of medication.*

*I want to be seen as a child ... Not just a  
condition or disability.*

*It's exactly about getting to know them  
very much. It make me very confident and  
comfortable – you need to get along with  
them and know them a little bit.*

Professionals highlighted the fact that this was a particular issue in acute settings, where time was far more limited and there was less opportunity to develop relationships with young people.

*I mean time is a real issue isn't it?  
Having children with physical or learning  
disabilities ... they're going to need more  
time for appointments because you're going  
to need any communication aids and that  
type of thing.*

It was felt that, generally, community staff had more time and were therefore more able to develop relationships and get to know the young person and communicate better with them.

### **Communicating with healthcare professionals**

All young people stressed the importance of the way in which professionals communicated with them. In particular, that they felt listened to.

Young people, in particular those with learning difficulties, stressed the importance of body language and especially eye contact and how clearly this communicated to them whether they were being listened to or not.

It was particularly important to young people that their own expertise was recognised. They spoke passionately about, and were very clear that they 'were the experts on, their own body. They recognised and valued the fact that professionals may have expertise in conditions, but also that they were the experts in their own health, their bodies and how the condition impacted upon them as an individual and their wider life. However, many felt that this was often not recognised or valued and wanted this to change.

*You know what you're going through ... know what's going on in your body.*

Young people wanted clear explanations, in ways they understood, with time for discussion and questions, so that they fully comprehended what was being discussed or explained. However, many indicated that they felt that they were not really listened to and their views were not taken seriously.

*They sort of ... they have made up their mind what must be wrong before I finish.*

Communication was also an issue raised by professionals who highlighted a need for more training and support to enable professionals to develop their skills in communicating with children and young people; particularly those with complex needs and communication impairments. It was felt that many professionals lacked the skills and confidence to communicate with young people who used different methods of communication, including informal and individual communication systems, and that this could lead to them making assumptions about a child's abilities.

*He uses a voice-output communication service and the amount of people who aren't willing to spend the time listening to him ... And that has a knock-on effect because then he doesn't want to use it in front of people he doesn't know. And then the communication breaks down. With people he knows, he's very communicative but the minute he sees doctors, consultants, etc. he just ... the curtains come down.*

*I think you're dealing with seasoned doctors who are doing their best but have no understanding of communication. If I said to a doctor 'why don't you use a picture system', there is not that training there for the health professionals and I find that happens quite a lot. I find that I'm leaving a young person and I'm thinking 'they're not going to be spoken to, they're just going to be wheeled about because they don't really have a strong enough voice', so I suppose that's a really big barrier for us.*

Communication seemed therefore to be a vicious rather than a virtuous circle. Lack of training for professionals on communicating with young people means that too many don't have the skills to find out what a young person has to say; and also don't always know how to make what they need to say comprehensible to the young person, so young people aren't in a position to join in with the conversation.

*... they speak amazingly quick.*

*Interviewer: How would you like the doctor to explain things to you?*

*Young person: Don't use long words ...*

*Interviewer: Do you feel like you can ask your doctor questions?*

*Young person: I could but he'd keep putting long words in it*

*My doctor uses loads and loads and loads and loads of long words and I can't understand.*

Where doctors supplemented verbal explanations with written information, thought was not always given to how accessible this might be for young people – the young people often reported being given information sheets which were complex and difficult to understand, and which weren't explained to them. They felt that using pictures and symbols to facilitate communication would be beneficial.

*Yeah, sometimes the things they come out with, they blow you away. They don't give me much paper stuff, but the things they do it's like I've found... I don't understand it, it's so dense I just don't want to read it.*

*Well at first they gave me a leaflet which I was looking at, but then we started talking about it, so that was better because the leaflet was just awful. So once we started talking, it was quite easy to make a decision [about what medication to take].*

Not having the time and space for discussion with healthcare professionals impacted heavily on young people's confidence and their understanding of their condition, treatment and support needs. They felt frustrated and disempowered at having to rely on family or support workers to attend appointments with them and explain to them afterwards what had been said, with many saying that if only the professionals could use simpler language, they would be able to go to appointments independently.

*Use shorter words, but what mean the same thing, so we can understand easier.*

All young people highly valued being informed and involved in discussions and decisions. This made them feel valued, respected and increased their confidence, self-esteem and their ability to feel as if they could be more independent in managing aspects of their healthcare.

This feedback is supported by research into self-care support for children and young people with long-term conditions, which identifies the

critical importance of positive patient-professional relationships, ones where professionals:

*... actively listen to patients; ... allow time for discussion; understand how the person experiences their condition and their individual decision-making preferences; encourages involvement/participation and promotes individual control, self-efficacy and motivation.*

**(Kirk and others 2010)**

Young people talked at length about how much confidence it takes and how difficult it can be to speak up, and be more involved, in discussions and decisions about their healthcare. Many young people told us that throughout their childhood they had no opportunity to do so yet, when they became 18, all of a sudden they were expected to take full control, speak for themselves and be 'an adult'. Young people wanted support to gradually increase their levels of involvement, understanding, skills, control over their healthcare and treatment, and confidence, and felt that this should start from a young age.

### **Who's communicating with who?**

Another key issue that prevented young people communicating with professionals was that the majority reported that they were excluded, as communication was between the professional and their parent or carer. This caused high levels of frustration and meant many young people felt patronised. This was particularly the case for young people with learning difficulties, who repeatedly expressed that it was their parent or carer that communicated with healthcare professionals.

*I want to [speak to professionals]. It's quite difficult. But it's partly my parents' fault and also the doctor, because you just want them to address you and ignore Mum and Dad. But they always talk to Mum and Dad.*

*I was just like ...[to the doctor] 'you just asked me something and you just immediately go back talking to my mum. How are you going to know what I'm on about if you just talk to my mum about it?'*

*I don't know. I really don't know [why professionals speak to parents]. Because we're the ones who know about our body ...*

*I feel like most of the time I'm sitting back watching.*

*It makes you feel sort of young, sort of like you're only like a little boy. Because your parents are talking to the doctor and making decisions without you. It's like you're not even there.*

The experience of the young people we spoke to is supported by wider research (see Cahill and Papageorgiou 2007). For instance, in an analysis of 105 video tapes of doctor-parent-child consultations, Tate and colleagues (2002) found that both adult participants control the interaction and treat the child as a 'passive bystander'.

The professionals that we spoke to felt that, again, this issue partly came down to skill and training.

*One of the problems is skill ... where the child has a MLD [moderate learning disability] the doctor doesn't feel able to start drawing pictures, explaining very simply. Then parents are over-protective ... the doctor asks the child a question and the mother answers.*

Many young people talked about how, given the right support, they could be more independent with their healthcare needs, yet they were disempowered by adults giving them too much support, taking away their responsibility, speaking for them. They found this demotivating and, in some cases, they explained that this meant they had now stopped trying to make an effort to be more involved.

*Young person: Just leave it to my mum.  
Facilitator: So you tend to sit back and let your mum do it?  
Young person: My mum can do it.*

*Just have to trust a doctor to get it right.*

This was a point which also came up in discussions with professionals.

*Many young people don't have the confidence to ask questions when they don't understand something. When asked what they do in these situations, they say 'we ask mum'.*

This manifestation of 'learned helplessness', the sense that their own contribution has no influence over future events (Seligman 1975), is problematic in that, in addition to reducing the contribution that young people are willing to make (Weisz 1979, Mulderij 1996), it leaves them ill-prepared for transition to adult services when greater expectations are likely to be placed on them.

Furthermore, young people clearly valued being spoken to directly, and having support and encouragement to enable them to develop their ability to see doctors independently.

*... it makes you feel more confident if they're speaking to you and you're speaking back and making your own decisions.*

*Young person: They tell me to go by myself to get more independent.  
Facilitator: How does it feel to go on your own?  
Young person: I can actually get a say in edgeways!  
Facilitator: And what was it like before?  
Young person: My mum always talks like without me being there.  
Facilitator: And how does that make you feel?  
Young person: Err .... Quite embarrassing.  
Facilitator: Now you get to talk to them yourself, how does that feel?  
Young person: More relaxed and I can get my head sorted.*



Tate and colleagues (2002) found that children were more likely to contribute when the doctor was supportive of their involvement; and most likely to be involved where both adults were supportive of them taking part.

### Explaining procedures

Getting communication right, involved more than talking to the right person and using the right language. Many young people with learning difficulties expressed how they often felt scared or confused in appointments. This seemed to be a particular issue with routine procedures, such as blood pressure readings, where professionals might make an assumption that the young person understood what the procedure was and why it was happening, and therefore conducted it without any explanation. In such instances many young people reported that they felt unable to question what was happening and so accepted the procedure, then worried about what it was afterwards.

*Facilitator: If you were feeling a bit scared, would you be able to say 'hold on a minute ... What are you doing?'  
 Young person 1: I wouldn't.  
 Young person 2: I'd just respect him [the doctor].*

Where procedures were explained, young people wanted professionals to be honest.

*What's the point in saying it won't hurt when it's a huge needle and you know for a fact it will hurt!!! Be a bit more truthful... 'hello, yes it might hurt a little bit' ... that would be more truthful than saying it won't hurt a bit.*

## Support in managing independently

### Expectations

Young people frequently told us that they felt that professionals saw them as unable to make their own choices and decisions or unable to 'cope' with the gravity of situations and decisions. They felt that they were protected yet judged, and assumptions were made about their ability because they were both a child and disabled.

*I don't think they [doctors] think that we are able to make decisions for ourselves.*

*Doctors ask parents or carers opinions ... because they think that the parents are more mentally capable of making that decision.*

*I don't like it when they make a judgement – like 'so they're disabled they don't have a clue what they're on about'.*

*It's to do with culture. Yeah ... How people see disabled people. You have to go 'yeah I'm still here. I might be different but I'm still here!'*

*[the doctor] Thinks I'm not very good with my health, but I am. Makes me feel a bit upset.*

Young people wanted support from an early age, to enable them to gradually increase their independence. This included going to appointments independently, managing their own medication, and making decisions about treatment.

Professionals felt that the way in which care was delivered needed, from the earliest age, to encourage the child or young person's involvement, empower them to take control and responsibility, and develop their confidence to believe they can take control. They felt that if young people were the passive recipient of care throughout their earlier life, this would have a significant impact on their self-esteem, confidence and expectations – and could thus set them on the trajectory to dependence, rather than independence.

However, this support also needed to be provided to parents – to enable them in turn to support their child to develop their independence and to see their child as able to take more control.

*Children need to be taught more independence skills ... They need to be more engaged too ... parents and young people are the experts, but they need support to build their confidence, understanding, and ability to manage their condition.*

*If you intervene earlier on, to get them managing it earlier on, then they gradually take more and more control. But to suddenly teach someone, if we've done it for them all those years and suddenly now it's your turn ... if they've been brought up that way ... if they're aware of their medicines and why they're taking them, it's a lot easier than suddenly changing the goalposts and treating them differently overnight.*

*So it's about thinking about it way before it comes to it ... Thinking about those who get injections ... if they're able to give their own injections then really the parents can step back more and more. It's about partnership... between children, us and their parents.*

Another key influence on young people's expectations and independence was identified as whether they access universal or solely specialist services. Some professionals felt that those children who accessed predominantly universal services, who were living more 'ordinary lives', had much higher expectations of their own independence. Whilst recognising the value and need for specialist services, they felt that children who solely accessed specialist services were much more dependent and had very different expectations of their independence.

*The kids I see [with long-term health conditions] who are joining in mainstream community activities tend to get a broader range of experiences [which impacts on their independence skills]. Whereas those who have been brought up with more specialist services all around them, and this is all they've known, become much more reliant and dependent. The ones that go to their local youth clubs or scouts for instance are very different – and you can tell by their social interaction and communication, and independence with their condition.*

### **Access to support**

As they were increasing their independence and taking more control, young people said they valued having someone there to support them in their appointments. This acted as reassurance and enabled them to refer to someone else if they got stuck – while still being the one taking the lead and speaking to the healthcare professional. This person could also then be there for them afterwards to talk about what happened in the appointment.

*On the way home my mum will have to explain my needs and that's that and that's that.*

Young people valued support from their peers. This enabled them to learn more about their specific condition and share common experiences with others in a similar situation. This could be face to face or through, for example, condition-specific organisations and websites.

*... and also I've had um, support ... like there's an organisation that specialises in helping people with my condition – the Brittle Bones Society – and it gave me loads of different, like, descriptions that you can understand about your condition. Um, what treatments there are and stuff like that, so they really helped me in doing that.*

*This organisation has a chatroom for people with my condition and we can chat about general stuff like sports and weather, to stuff like ... that none of the other people understand. Stuff like that.*

Some young people mentioned they could access support from health counsellors, who support them by going with them to appointments, if they didn't want to go with their parent or carer. Young people with learning difficulties, in particular, stressed the importance of support from family, friends and support workers in enabling them to manage their condition.

Those young people who had the support of a dedicated team in their transition to adult services, reported that it helped to develop their confidence and independence, learn about and manage their condition, and work towards realising their aspirations.

*[It's good when they] make you have goals – it might take time but you've got to have goals to get there ... It makes you more determined – I see the goal and I want to get there.*

Some young people, who were less lucky, reported the dramatic change they experienced in moving from children's to adult services. Suddenly, they were the ones being spoken to, asked questions and expected to be independent. Many felt they lacked the skills and confidence to cope with this. They wanted support from a young age to gradually increase their involvement, level of control, decision-making skills and confidence.

*It's a bit more frightening because they talk to me rather than my mum, so I'm trying to get a bit more confident. Trying to sort of speak to them rather than looking at my mum.*

*... it would probably be a good idea [to gradually learn to ask questions/be more involved] – if you get more confident then when you go to adult services you know what to do, to speak up when they talk to me.*

Young people really valued support to make their own choices and reported that it had a positive impact on their confidence and self-esteem.

*I think I have been involved in most of the [decisions] that have changed my lifestyle. Because, I have like ... ventilation at night now and about 6 months ago that was when they said about it and sort of said, you don't sort of need it right now, but they said do you think you'd like to start it. And I was like it would probably be good to start now, because it won't change. If I get used to it now, it would be good. That's probably the main one I decided.*

*... [being allowed to make decisions] ... um, it sort of made me feel quite mature I suppose ... It was good to make a decision.*

The issue of 'what is independence' was raised by several professionals. They felt many young people had an understanding of independence as having to physically do everything for yourself, which impacted on their perceptions of their own current or future independence. They felt strongly that young people need to be supported to understand that independence is about leading your care – influencing choices – being in control in whatever way is appropriate, rather than physically having to do everything for yourself.

*Is managing your condition not having any adult support or is managing your condition leading the coordination of that? And being able to say 'this is how I want things to be' – many young people don't grasp this ...*

*It's around what they can do ... they can direct their support workers, keep track of when their appointments are, that you see the letters, but you can be in control.*

The need to start to involve, engage with, and support children and young people to take more control of their healthcare and condition was a strong theme running throughout all of the focus groups. Children need to be supported right from the start, to gradually take more and more control

of their healthcare – starting from developing and understanding their condition, through to taking control and influencing decisions rather than expecting them to suddenly become independent and confident enough to do so at 14 or 18.

*When she suddenly went over into adult services, it was this big ‘woah’ – suddenly the doctor was speaking to her and she didn’t know how to take it. There was a lot to take on board because they were changing her medication regime, she was going through her GCSEs, she was being told she was an adult, lots of environmental factors ... she’s 21 now and I think she’s only just now starting to come to terms with managing her own healthcare but its been a difficult process.*

### **Disempowering young people unintentionally**

Many professionals were also very aware of the potential to disempower children and young people unintentionally – particularly those with more complex health conditions – by providing such high levels of support or being so focused on ensuring their condition is effectively managed from a medical point of view, that the young person’s role within this is lost.

This impacted on young people’s perception of their independence and responsibility for their own health. For example, if young people have always had others taking responsibility for their health, this can stop them asking questions or developing their own sense of responsibility for their health, as this has always been done for them.

*One young person has absolutely no inclination to ask what’s going on because she doesn’t need to. We’ve facilitated absolutely everything and taken away the need for her to ask why we do certain things. She’s just totally accepting of it, because it’s been that way all of her life.*

Disabled children and young people are at greater risk of developing ‘learned helplessness’ (Weisz 1981) and, as identified earlier on in this report, professionals need to be aware of this danger since it can lead to young people taking less rather than more of a role in discussions about their own healthcare. It is also likely that this would then impact on adherence to any treatment regime.

Thus, professionals need to be clear about the boundaries of their role and the parental role; be aware of the unintended consequences of their actions; be aware not to disempower young people and their families; and ensure that the developing independence of the young person remains at the centre of all support provided.

This was noted as a particular issue in relation to discharge from tertiary care. Professionals felt that, too often, care packages negotiated for discharge left little role for parents and therefore little room for the child to take responsibility as they grew.

*It gives parents unrealistic expectations, it frightens them and it takes away their parental role. If you can’t trust ordinary adults to look after their child, how do you trust the child to look after themselves? [Said in reference to a child going home on ventilation.]*

Given the importance of the parent’s role in supporting increasing independence, discussed earlier, this is a significant issue. Professionals felt that if parents were told that only specialist nurses could support their child, not only does it distance them from their child’s care but it very much lessens the likelihood of that parent seeing that, actually, their child could take control of or influence decisions about their healthcare, and be active in the treatment of their own condition. It underlines the critical importance of getting ‘discharge’ right, not just for the child at that point but for their future development.

Professionals recognised that parents needed support to gradually separate from their child and encourage their independence – to begin to see their child as a young adult who can be independent.

*Parents have spent years and years being told your child can't do this, your child can't do that, so it's difficult for them to then see their child as being independent.*

Addressing this issue is therefore a critical part of the foundations of good transition for disabled children and young people moving into adulthood.

### **Managing medication**

One of the ways in which many young people did take control over the management of their own health conditions was self-medication. Many reported being able to manage their own medication and on the positive impact this had on their confidence and self-esteem.

*[It makes me feel] ... more independent ... more grown up.*

There were some issues, however, for some young people who were at residential schools or colleges who reported that, whilst they were allowed to manage their own medication at home, they could not do so during term time. This had a negative impact on their self-confidence and self-esteem.

*I've got a good point to make! If you can take your own medication when you go home at half term yeah, and when you come back to college you've got to hand it in to staff, doesn't that prove a point that they don't trust you ... It's like knocking your confidence.*

*I mean at home I can take my puffer myself, but here I have to hand it all in, so it makes me feel not confident anymore.*

*[I'd change things so] that you can be trusted to take it everyday. So I can leave it in my room, lock it in my room, somewhere I know it is safe.*

It appears therefore that health and safety concerns in some settings are undermining young people's ability to develop and maintain their independence.

Conversely, young people and professionals discussed the fact that special schools can be a key place where young people can be supported to learn about their health conditions and gradually learn to take responsibility; for example, by learning to take their own medication in a safe, supportive environment where this can be supervised and their skills gradually developed. This was also noted as a key way to influence their independence at home: if you show young people how to do certain things at school then professionals can then work with the parents and young person to learn to do it at home as well.

In addition, it was felt that many mainstream schools are getting much better at supporting young people with health needs and that this could have a positive impact on children's independence and aspirations. However, support is needed for schools and staff, from health professionals, to ensure that they have the right skills to support individual children and young people and can encourage them to develop their independence.

Some PCTs (Primary Care Trusts) identified that this support is a key focus of their school nursing teams, who have placed an emphasis on educating other professionals involved in the young person's life rather than providing support directly. Hand in hand with this, has been a shift away from undertaking 'procedures' to making support for young people more normalised. For example, supporting children with catheters in the school toilet rather than 'behind a curtain in the medical room'.

*I taught the children how to care for themselves ... and actually got some children to learn how to do their own gastrostomy feeding. But it takes a long time ... I think it took me about a year to get to that stage. In acute type settings there is just not the time to do that but that's where you need that kind of support.*

Teaching children and young people how to manage their own medication was also seen as critical to their taking ownership and lessening the likelihood of non-compliance. Rebellion and denial are normal parts of adolescence and thus it was felt that children need to be supported from an early age to feel ownership of their condition; understand it; be involved in decisions about it; and understand the purpose of the medication they take and the consequences of not taking it.

*Teenagers want to be like everyone else, they don't want to be 'different' and seen to be taking medication, so they quite often reject medication or treatment programme.*

*They also have peer pressure, social pressure about it not being normal and one instance in particular I think about, and it actually came back to the fact that nobody had explained to the kid how important it was and why. I think partly that is because we don't want to scare them and the other bit is because it has already been explained to the parent in the past. If you understand the importance of taking your medication and you are able to make an informed decision then you should be give as much autonomy as possible, but there is no use giving autonomy and not letting them know what the consequences might be.*

The Department of Health (2004b) is clear that adolescence poses a special challenge when it comes to compliance with treatment: with evidence showing low rates of compliance in, for example, cystic fibrosis, epilepsy, diabetes and asthma. Partnerships with young people are vital if we are to prevent them opting out of treatment for a decade and achieving poorer health outcomes as a result.

### **Young people's understanding of their condition**

Many professionals felt that it was vital to ensure children and young people had an understanding of their condition; and were concerned that, although many could express how their condition affected them, they did not have a wider detailed understanding of what their condition was.

One of the main issues seemed to be that often the child has never officially received their own diagnosis; it has been given by the doctor to a parent when the child was young. It has not then been given formally to the child as they have grown in understanding. As such, many children and young people have a very individualised understanding of their condition, and little awareness that others have the same condition, which can often mean they lack a positive self-identity.

*I always felt that for a lot of the children and young people their parents have received the diagnosis on their behalf and there was no – and this is a very personal thought – but I always felt that for a lot of young people they needed their own diagnosis and at some point to receive that diagnosis and have the opportunity to have the information.*

It was felt that many professionals and parents want to 'protect' young people from the truth about their condition, but that this needed to change to enable young people to develop a positive self-identity and feel ownership over their own bodies and health. In addition, without an understanding of their condition, young people are unable to make informed decisions about their healthcare or treatment.

Thus, they need to be supported to gradually develop their understanding of their condition as they grow older and develop their confidence and independence

*A lot of people wait until the kids start asking the questions. But if they're not asking the questions, they're not going to get the answers. Many young people don't feel able to ask the questions. Maybe it's because they're so dependent on others ... so we need to make sure we support them to develop their understanding and introduce this to young people, rather than waiting until they ask.*

## Tools and approaches that support independence

### Health passports

Several young people spoke positively about using a health passport. This was a hand-held record – completed by the young person, family and professionals – that includes information about them, their condition, medication, medical history, what support they wanted and how they liked to be supported. This was a way of preventing them from having to repeat themselves and enabled them to feel more in control of their condition and the information held about them. It also enabled them to direct their support more independently.

*... basically it has a summary of what your condition is, what my ambitions are, and also it describes what I can do and what support I need. It also has the context for doctors and other people who support me.*

Hand-held records were identified by professionals as one of the most effective tools to encourage and support young people's independence and control over their healthcare. These took a variety of similar guises, including communication passports; care plans; health passports; and All About Me books. These tools, developed in partnership between children, their parents and professionals, are owned by the young person and can contain various types of information about the young person, their health care and treatment. They can include, for example, past procedures; medication; appointment times; letters from professionals; basic personal information; likes and dislikes; methods of communication; professionals they have contact with; their abilities and their dreams and aspirations.

These tools empower young people, by preventing them from having to continually repeat their history; aid their memory about their condition, past treatment and support, or any medication that is difficult to remember the name of; enables professionals to develop a clear understanding of how to support the young

person; aids communication; and, as it is owned by the young person, enables them to direct their own support and feel more in control.

### Going to appointments independently

Enabling young people to develop the skills and confidence to go to appointments independently was raised as a key issue. Professionals understood parents' desire to go to appointments with their child and, for example, felt that it was not just about telling parents not to come – but to encourage a gradual transition, whereby the child took more responsibility for communicating with the professional directly, rather than communication happening purely between the professional and parent. Thus for example, until the young person has the confidence to visit independently, their parents can support them and act as a prompt when needed; then shift to going with them but staying in the waiting room, in case the young person needs to call them in.

*We do things where the child comes in first, or parents and the child come in first, and then the parents leave the room and child stays behind and has the end of that consultation.*

*Starting early [name of doctor] is very much a case of 'they've got to take ownership of it because it's not going to go away' and she does work from a very young age of getting them to take responsibility. And even if parents are in the room and start talking to the child, she'll say 'I'm not talking to you, I'm talking to so and so' so she will actually address it. But she'll allow the parents to have a say too. And that's anything from the age of three upwards.*

*[Name of doctor] does a 'stool withholding' clinic, and the kids don't really want to speak about it in front of their parents ... they get really antsy about it, so he sends the parents off and has a man-to-man chat with them. And that seems to get a really good reaction from the children because they might not want to tell their mum something but they'll tell him because he's treating them like a grown-up.*

One area had developed a tool to facilitate young people visiting the doctor independently.

*We've created a leaflet that young people can take to the doctors, and the first bit is 'the reason I've come to the doctors today' so they can talk to someone and fill it in before they go. Then it says 'questions I'd like to ask' then on the back it's 'what did the doctor say/what's happening next'. It came about because a parent said to me 'he can't go to the doctors on his own, because he'll forget to tell me what was said – the doctor might say something really important about a medication change that I need to know about or help him at home to deal with.'*

Thus, the tool not only supports and empowers the young person but also acts as a reassurance to parents, as young people begin to become more independent.

### High expectations

Professionals identified that given the right support and approach, children can be involved in managing health needs and taking responsibility for this from a very young age. For example, there were many examples of children as young as four years old self-catheterising, and other children managing their gastrostomy feed. Thus, the emphasis should be on teaching children and young people to gradually take more and more control of the management of their condition based on high expectations of the child.

However, they stressed that expectations needed to be based on an individual child's ability and that there was no 'gold standard' for children to aspire to:

*We need to celebrate the little achievements, because all children make them – no matter how small. We need to compare their achievements to their own abilities, not those of other children or 'standard development.'*

### Empowering young people

Dedicated support to empower young people was identified as a key area of good practice to enable young people to develop their skills, confidence and control over their own health. The Staying Positive approach (part of the Expert Patient Programme) was identified as a key way of achieving this and enabling young people to access peer support. In addition, one PCT that was consulted had a dedicated empowerment project





for young people, which focused on developing young people's skills and confidence to manage their own condition; gain support from their peers; discuss how their condition impacted on their wider life; and have access to workshops on a range of key issues identified by young people, such as self-esteem and sexual health.

### **Levels of involvement**

There was a concern from professionals that there was an all-or-nothing approach to involving children and young people in their own healthcare. That if young people were not 'Gillick competent' – demonstrating sufficient understanding and intelligence to understand fully what is being discussed or proposed – then they were assumed not to be able to have any involvement.

*We have to accept that the level of participation is not what they [professionals] are expecting. Sometimes, it's not going to be a yes or no answer. It's not going to be quite as clear-cut as being able to make a decision about what treatment you have. The level of participation is going to be different for each young person and at the moment it's almost like 'this young person can't participate because they have this learning difficulty therefore we won't include them', when actually ... when I think they can be included at some level, at some point within the process.*

Professionals therefore wanted a tool that 'breaks down the different levels of participation for them [professionals] and helps them to think through that even if they [young people] can't cognitively make that decision at least they can be informed as best as they are able about what is going on'..

# Conclusions

These findings are unlikely to shock those working with disabled children and young people, although they may be dismayed by the pervasiveness of poor experience. However, what can be seen as encouraging is that there is nothing preventing services from getting it right. No massive investment of money is required. Practice will not improve across the board overnight but awareness-raising, professional development, availability of the right tools and resources, will all go a long way towards transforming young people's experience of health consultations and services, and will give disabled children and young people more of a say about what those services are and how they're delivered to them.

Whilst improving things is not costly, there is a cost to leaving things as they are.

Young people who are being enabled to take the maximum possible responsibility for their own healthcare are young people who are signed up to their own treatment programme and more likely to understand the importance of compliance with that programme. Research indicates that the improved clinical outcomes that result from compliance with medication alone, lead to significant cost savings (Sokol and others 2005). These savings come from reduced clinically significant events, fewer emergency department visits, fewer hospitalisations, fewer consultations, and generally reduced morbidity and mortality.

The government has identified, as a priority for the NHS, the instituting of shared decision making – no decision about me without me. The White Paper on health, *Equity and Excellence: Liberating the NHS* (2010) is clear that involving patients in their care and treatment improves their health outcomes, boosts their satisfaction with services received, and increases not just their knowledge and understanding of their health status but also their adherence to a chosen treatment.

This report covers the complete spectrum of disabled children and young people and recognises that, for some, making decisions and being more independent will not be attainable in terms of their own cognitive impairments. The report addresses the issues for these children and young people and identifies ways of improving decision-making by parents and others to ensure that the child's best interest remains central.

Giving disabled children and young people greater control over decisions affecting their health is important at all stages of a young person's development but becomes critical as young people approach transition to adulthood and the expectations of their role changes. As pointed out in the Department of Health guide, *Transition: Getting it right for young people* (2006b), as they get older, children need to be involved increasingly in decisions about matters that affect them, so that by the time they are young adults they have learned to take responsibility for their own health.

*Young people move from a children's or young person's clinic, where they may have known their paediatrician and many other staff through much of their childhood and teens, to bigger, busier adult clinics, where they are surrounded by much older patients whose diseases may be very different from their own; they are less likely to see the same doctor on each visit; consultations may be shorter; and support and advice from staff may be less readily available.*

*For these young people, a transition programme between paediatric and adult-oriented health services must provide co-ordinated, uninterrupted healthcare to avoid negative consequences, ranging from psychological distress and anxiety to medical catastrophe or premature death.*

***(Transition: Getting it right for young people, Department of Health 2006b)***

Whilst much focus has been given to improving transitions for young people, for many, they are still far from perfect. However, the more that has been done to empower young people the better able they will be to weather any storms that transition may bring and the more ready they will be to take on the increased responsibilities that adult services expect of them.

There are cost savings to be made in ensuring that we do not over-professionalise care. Whilst it may seem safer and quicker in the short term to carry out procedures for parents or children and young people, it is far more cost effective as well as empowering to ensure that, where possible, they can administer them for themselves (for example, Derrickson and others 1991). Building over-dependence is not only de-skilling for children and young people, it is extraordinarily costly and has an impact long into adulthood. As can be seen from some of those who contributed to this report, in the very worst cases it can distance parents from their own children. It creates a situation where parents feel unqualified to care for their own child, which in turn is likely to make them anxious about their child taking on more responsibility for their care as they grow.

More thought needs to be given to supporting young people in their burgeoning independence. Parents of disabled children may struggle to accept their child's increasing need for independence. If a young person's level of physical dependence or their need for support has not changed, it may be difficult for parents to recognise that they are growing up. This makes it even more critical that medical professionals working with children do all that they can to encourage young people's independence. An important part of this process may be ensuring that at some point they themselves receive their own diagnosis, as a rite of passage.

A critical underpinning factor in empowering young people is communication. This report demonstrates that there is a long road to be travelled. Currently they too often feel as though they are the subject of, rather than participants in, medical consultations. Focus needs to be given to training professionals, and to giving support to professionals and young people, to facilitate communication, with the expectation that for young people with additional communication

needs preparation for the consultation will be needed on both sides. It is vital that health professionals look beyond the capacity to make and readily communicate decisions to identify what is being communicated and the implications for patient care.

# Recommendations

- ◆ The development of an NHS e-learning module on communicating with children and young people with learning difficulties and communication impairments. This recognises the need for health professionals to develop skills in alternative methods of communication (non-language based) and to develop a knowledge of resources, which can then be used to explain health concerns to disabled children and young people with cognitive impairments and or learning disabilities.
- ◆ The development of resources to address communication with disabled children and young people in hospitals should be undertaken across children's and adult services. Many hospital trusts have developed resources to assist in better communication with disabled children and adults; and a number of trusts have appointed a 'liaison' person to promote communication with disabled adults. Work within trusts should be shared across children's and adult services.
- ◆ Health trusts should consider building protocols into the system for setting up appointments which would support preparation for the consultation. For instance, parents and young people should be encouraged to develop an agenda for their consultation (Sepucha and others 2002) in order to maximise the effectiveness of the consultation for both clinician and family.
- ◆ As the young person reaches adolescence, the clinician should explore with the family the formal handing over to the young person of their own diagnosis. At the same time, clinicians may wish to explore with young people whether or not there is someone other than their parent who they would wish to have support them in either preparing for attending appointments.
- ◆ As set out in the Council for Disabled Children guidelines on the discharge from hospital of children and young people with high support needs: at the stage of discharge from tertiary care after diagnosis, thought must be given to the way in which care packages impact on family life and ensure that they do not disempower families or young people.
- ◆ Performance assessments for staff working with disabled children and those with long-term conditions should include a focus on the extent to which they are fostering self-care and independence.
- ◆ Settings should ensure that protocols for the safe management of medicine maximise young people's independence and control around self-medication.
- ◆ As set out in the National Service Framework, consultations with all health professionals must place the child at the centre. Every effort should be made to enable young people to make a contribution to the consultation; and any decisions made should take into account any preferences expressed by the child or young person.

# Resources

All of the resources in this section can be found on the Council for Disabled Children Website [www.councilfordisabledchildren/myway](http://www.councilfordisabledchildren/myway)

## Hospital passports

Hospital passports have been developed along similar lines to communication passports but, as they are used when disabled children go into hospital, they focus on the information that is needed when the child is in a 'health environment'. Hospital passports are also known as All About Me books or health passports.

Communication passports are described as:

*... a special way of sorting information. They don't contain ALL the available information about a person but KEY information about day-to-day 'need to know' things. Passports are about collecting information from the people who know the person best, observing, analysing and then distilling and organising all of this information in new ways. In other words, a Passport is not a list but a synthesis of information useful to help other people to help the person to 'be the best he/she can be.'*  
**(Millar 2003, p.6)**

Hospital passports have been developed by a number of trusts, local authorities and third sector organisations across both children's and adult services. They vary in length and content – but the majority will present personal information about the child, outline their communication methods, their likes and dislikes, and their health and support needs. They serve two purposes, firstly to present information so the child, young person or family do not have to keep repeating their 'story'. Secondly, and very importantly for children who use alternative methods of communication, they explain how the child

communicates so that staff can recognise when a child may be in pain or discomfort, is hungry or thirsty, etc.

Passports are always written in the 'first' person – so they depict the world from the child's viewpoint and this helps to retain a 'child-centred' approach. A number of passports across both children and adult services are based on the 'traffic light system':

- Red – things you **must know** about me
- Amber – things that are **important** to me
- Green – my **likes and dislikes**.

Examples of passports based on this system are to be found in:

- ◆ Cambridge University Hospitals NHS Trust/ Addenbrookes hospital
- ◆ NHS Knowsley and Knowsley Council
- ◆ County Durham and Darlington NHS Foundation Trust and Darlington Borough Council
- ◆ Mid Cheshire Hospitals NHS Trust and Cheshire and Wirral Partnership NHS Trust.

There are a number of other models of 'hospital passports' that have been developed for disabled children. Examples of these include those in:

- ◆ Birmingham Children's Hospital
- ◆ Walsall – This passport was developed by the transitions team and is used in a variety of situations: meeting new health professionals; applying for a place at college; taking to a job interview; supporting a DLA application. Young people have an electronic copy so that they can update it.

- ◆ Wraparound and Craigavon Area Hospital, Northern Ireland.

A range of templates are offered on the CALL Scotland website to assist in developing communication passports: <http://www.communicationpassports.org.uk/Resources/Creating-Passports/>

## Health Action Plans

Health Action Plans (HAPs) were introduced by the Valuing People strategy in 2001. A HAP is a document that is prepared by or with a person with learning disabilities and covers information about their health and health choices. It was intended that all adults with learning disabilities would have a HAP. However, because of the extensive nature of this plan, this intention has not been realised. They were introduced mainly into adult services – but some transition teams started to use them as well.

A HAP will cover more than a hospital passport – it is a plan about what is needed for a person to remain healthy, including the support which a person may require. It will also document ongoing health appointments, concerns and treatments.

Some examples of HAPs for adults have been developed by Mencap and Bedfordshire Health; and for children by Salford Community Health and NHS Ealing together with Treat Me Right.

Resources that play a similar role to HAPs have been developed in children's services – although by another name. For example, NHS Croydon have developed a robust Filofax style A5 folder called 'My Health Book' for young people from 14 years. A second example has been developed by Nottingham University Hospitals NHS Trust for use with children on long-term ventilation.

## Emergency Healthcare Plans

An Emergency Healthcare Plan contains – in a very brief format – all of the key information about a child's condition so that, should they have a healthcare emergency, they get:

- ◆ the right treatment
- ◆ as promptly as possible
- ◆ with the right experts involved in their care.

In an emergency, when medical professionals may have to make very quick decisions about administration of drugs or other medical interventions, it is vital that they don't have to go searching through lengthy documents to find the information they're looking for.

Plans can also provide support to parents in a medical emergency – sometimes children with complex needs or rare disorders are on very atypical doses of a drug or on a large number of different medications. In a stressful medical emergency situation, parents may have difficulty remembering all of the drugs and correct dosages. Also, if dosages are atypical they may find that medical staff question their recall. Emergency Healthcare Plans set out all of this critical information and, because they are signed off by a senior medical practitioner, they are readily accepted by medical staff.

There are a number of Emergency Healthcare Plans, for example those of the:

- ◆ East Midlands Children and Young People's Palliative Care Network – Personal Resuscitation Plan
- ◆ Royal Liverpool Children's NHS Trust
- ◆ City Hospitals Sunderland NHS Foundation Trust.
- ◆ NHS South Central

## Leaflets – for going to appointments or into hospital

Leaflets that have been designed to help disabled children, young people and their families to take more control and increase their participation when attending hospital or health appointments. Examples of these types of leaflets are as follows.

1. The Department of Health has a leaflet which is used by a number of trusts. This leaflet details the type of questions to ask when going to a hospital appointment.
2. Walsall transitions team have designed their own leaflet – to be used by young people when attending appointments.
3. Hertfordshire Community NHS Trust have a Grab Sheet, which families take with them when their child is admitted to hospital and covers similar areas to those covered by hospital passports.
4. The hospital trusts in Staffordshire, Shropshire and Telford have designed a leaflet reminding people what they need to take with them or find out about when they are going into hospital.
5. HFT, a charity which supports people with learning disabilities, has designed a very comprehensive guide for both hospital staff, paid carers and families about admission to hospital. Although the guide predominately focuses on adults, it provides some useful resources and ideas to be used with disabled children and young people.

## Information leaflets

Leaflets and storybooks have been developed that explain different conditions in a way which is appropriate to children and young people. These have been developed by a range of organisations, for example:

The Royal College of Anaesthetists – <http://www.rcoa.ac.uk/index.asp?PageID=1520>

Diabetes UK – <http://www.diabetes.org.uk/Guide-to-diabetes/My-life/>

Cystic Fibrosis Trust – <http://www.cftrust.org.uk/aboutcf/publications/booklets/> Epilepsy Action – <http://www.epilepsy.org.uk/kids/>

The website for Easy Health ([www.easyhealth.org.uk](http://www.easyhealth.org.uk)) provides links to a wide range of leaflets, written by them as well as a variety of other organisations and trusts. Many of the leaflets offer both a written and an audio version. Although very adult focused, the website does provide some useful resources for staff developing their own child-focused material.

## Useful websites

A number of organisations have started to develop resources which can be used with children who do not communicate easily using the written word.

- ◆ Oxfordshire Total Communication's website details ideas and resources for using alternative methods of communication: <http://www.oxtc.co.uk/resources.shtml>
- ◆ BILD's website outlines some useful communication tools and approaches: [http://www.bild.org.uk/humanrights/docs/seldom\\_heard/section\\_3/3\\_2/Resourceonecommunicationtools.pdf](http://www.bild.org.uk/humanrights/docs/seldom_heard/section_3/3_2/Resourceonecommunicationtools.pdf)
- ◆ Support for Living (Ealing)'s website gives information for developing hospital passports and other material for use in a health setting: <http://www.supportforliving.org.uk/projectsandinitiatives/treatmeright/elsablog.htm>
- ◆ They also provide a bank of pictures for use in developing your own material: <http://www.supportforliving.org.uk/projectsandinitiatives/treatmeright/communication%20book%20part%202.pdf>

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It's about how I can live with  
my condition but still have  
a good time and just be  
a young person

