

COMMON ROOM

TALKING ABOUT RIGHTS THE VIEWS OF YOUNG PEOPLE WITH LONG TERM HEALTH CONDITIONS

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“I think sometimes people think children’s rights are something extra, an add-on. They’re really just the starting point. They should just be, like, how people work with children...”



COMMON ROOM

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ABOUT THIS REPORT

COMMON ROOM

- Common Room promotes shared decision-making, person centred practice, and the views and expertise of children and young people with lived experience across disability, health, and mental health.
- Here at Common Room we believe that we all just have different perspectives of the same situations. We look past labels such as patient and professional, adult and child, and help people to connect as people. *We think it's better to work together to find our common ground, use our collective expertise, and be partners in change.*
- We believe that all young people should:
 - be actively involved in decisions about their lives, treatment and support.
 - be equal partners in policy, research, practice and service improvement programmes.
 - have a voice about social, policy and practice issues that affect their lives and for their views to influence policy, practice and service improvements.



Thanks to the staff and young people from Investing in Children and Young People 4 Change - Nottingham University Hospitals Youth Service. Without your views, experience and expertise this report wouldn't have been possible.

Thank you also to Luke Tchalenko from Dust and Scratches Productions for the film work.

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ABOUT THIS REPORT

FOREWORD

Hi, I'm Amy and I have a long term health condition called Vocal Cord Dysfunction. As a young person, I struggled with a lot of the issues tackled in this report – like not being able to achieve at school due to time spent in hospital, feeling the odd one out in PE lessons and finding health services hard to access. At the time, I didn't understand what my rights were and what that meant for my life, so I couldn't fight to get what I wanted, needed and deserved.

Children and young people are often taught that they should passively accept whatever adults tell them to do. They are not taught to fight for what they need. Odd really, isn't it, because young people with long term health conditions are often fighting tooth and nail just to stay alive. It's easy to forget that these children and young people still have personalities, ambitions and a wish to 'fit in' – just like everyone else.

They should not be deprived of this. Every child deserves to be cared for in a way that takes into account their choices and individuality, their ambitions and needs. That's why I'm so thankful to the young people consulted in these documents. Their honesty about their experiences and simple tips to make services work really make it easy for commissioners to know what children and young people need. I hope this document informs the next generation of services, so that in future all children gets their needs (and rights) met.



Amy,
Common
Room Young
Advisor

ABOUT THIS REPORT

FOREWORD

Hello my name is Kath; I'm a Children's Nurse working at NHS England where I focus on improving experiences of care.

In 1989 world leaders decided that children needed a special set of rights just for them, the United Nations Convention on the rights of the child (UNCRC) with 54 articles, each distinct but all integral emerged. The UNCRC states the minimum basic human rights that all children are entitled to; it is ratified by 193 countries globally and the UK signed up to it in 1991.

As Health Care professionals we need to understand these rights, what are they and what do they mean in practice? If we understand them we can use them effectively to commission, design and deliver services in partnership to secure better health outcomes with and for children and young people.

Who better to explain what these rights mean and which rights are most relevant within Health Care than children and young people themselves? This resource is full on the views of young people and I'm so grateful to them all for sharing their wisdom.

Advocacy is an essential part of improving health outcomes; we can get smarter at advocating for and with children and young people when we use the UNCRC in collaboration with the NHS Constitution. Have a look too at the great work by the Council for Disabled Children and National Children's Bureau on children's rights in health care; they've explored what the NHS Constitution means to children and young people.

The future is IN our hands; let's work together with children and young people to make it the best it possibly can be!



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* www.councilfordisabledchildren.org.uk/resources/children-and-young-people-s-health-rights-in-england-shared-messages

ABOUT THIS REPORT

FOREWORD

Children and young people make up a significant proportion of the people who rely on NHS services but too often their needs are overlooked or secondary to those of the adult patient population when planning and delivering services.

While things have improved since 1995 when a senior nurse told the inquiry into the failings at Bristol Royal Infirmary, that “the majority of adult qualified nurses and doctors see children as small adults, who simply need smaller beds and smaller portions of food.” There is still no single shared vision of children’s rights across the NHS.

Our 6 reports on the Children and Young People’s health rights highlight how the current system of rights in the NHS

Constitution are written from an adult perspective without a clear message across policy drivers about how these rights should be translated for children and young people.*

The Report of the Public Inquiry into children’s heart surgery at the Bristol Royal Infirmary 1984-1995: Learning from Bristol

Children and young people are growing and developing individuals, not simply adults who lack capacity to make their own decisions. Their rights do not pass from their parents to them at their 16th or 18th birthday, rather there is a continual process of supporting children and young people to be as involved in their own health and care as possible.

Children and young people themselves are unsure about and are concerned that they’re not always being them. This uncertainly could cause additional anxiety and stress at already challenging times, and make young people less confident about using NHS services.

The UNCRC is an important part of creating a vision for children’s rights across the NHS, and listening to children and young people is at the very core of this process.

Andrew Fellowes, Senior Development Officer
Amanda Allard, Assistant Director
Council for Disabled Children

ABOUT THIS REPORT

TALKING ABOUT RIGHTS

Rights can sometimes seem like they are only words. But really, they are all the little, important things that make you feel good, and make the help that you get right for you.

Talking About Rights has been produced to help commissioners and healthcare staff to increase their understanding of specific articles within the United Nations Convention on the Rights of the Child (UNCRC) through the eyes of children and young people.

The report and short films are based entirely on the views, experience and expertise of children and young people with long-term health conditions (LTHC) and has given them the space to define how rights should be practiced by the services that are an important role in their everyday lives.

The relevant UNCRC articles are listed below; each will be addressed in detail in the body of the report.

- **Health**

Article 24: Health and health services: Every child has the right to the best possible health.

- **Views of the child and freedom of expression**

Article 12: Respect for the views of children and young people: Every child and young person has the right to say what they think in all matters affecting them, and to have their views taken seriously.
Article 13: Freedom of expression: Every child must be free to say what they think and to seek and receive all kinds of information.

- **Education**

Article 28: Right to education: Every child and young person has the right to an education.
Article 29: Goals of education: Education must develop every child's personality, talents and abilities to the full.

- **Play and leisure**

Article 31: Leisure, play and culture: Every child has the right to relax, play and take part in a wide range of cultural and artistic activities.

Ref: UNICEF (2012) A summary of the UN Convention on the Rights of the Child

★ www.unicef.org/crc/files/Rights_overview.pdf



Link

ABOUT THIS REPORT

INTRODUCTION

The right to the best possible health isn't just about the best treatments or medications. It's also about how we experience the care, treatment and support we receive. The right to the best possible health also refers to:

- respecting our right to be heard and involved in decisions about our support and care (Article 12, p.13 Talking About Rights).
- understanding how our health and healthcare can affect our right to education (Articles 28 and 29, p.17 Talking About Rights), and our right to play and leisure (Article 31, p.11 Talking About Rights).
- making sure disabled children and young people have the right support, equal access to healthcare services and the same opportunities as non-disabled young people (Article 23).

Throughout the process of compiling this report, children and young people expressed that rights are at the heart of all good healthcare services. Young people need to know and understand what their rights are, and to see that these are respected and valued.

Children and young people's thoughts and comments are presented over the following pages in relation to the UNCRC articles (referred to on page 4) within the four areas of Health, Views of the Child, Education and Play & Leisure.

Let us know what our rights are so we know that we have rights!

Sometimes, if you talk about rights, they think you're being difficult.

I think sometimes they think your parent is the patient, not you.

— ARTICLE 24 —
THE RIGHT TO THE BEST POSSIBLE HEALTH



— ARTICLE 24 —

THE RIGHT TO THE BEST POSSIBLE HEALTH



When asked about their rights in relation to health care, young people expressed their need for care and support which is timely and accessible. They want healthcare plans which are fit for purpose and which are personalised to them and which focus on their strengths. They want healthcare information which is straight-talking and addresses other relevant health issues and concerns beyond their condition.

You sometimes don't notice rights when they're there. That's just a good service. You only really notice rights when they're not there... that's when you really feel it.

The right to the best possible health means... getting help when we need it

The right to the best possible health means being able to access the correct service or treatment as soon as possible without having to pursue a battle due to “your number not fitting directly in a slot” or inter-service politics. It means I can be treated or maintained at the highest level of health possible without unnecessary deterioration as everyone should be achieving the same level of healthcare despite background, ethnicity, disability or geographical location.

A quick response to the situation. Like if you go to A+E or something and you say your asthma is really serious. A quick background, get straight to the doctor. They trust you know what you need.

- We need to know when our next appointment is in advance instead of having to wait to find out. This means we can plan our lives better, making us feel more in control and less anxious.
- It would be good if referrals were simple and easy so that we can access the services and support we need rather than having to battle the system.
- Keep waiting times for treatment or appointments as short as possible so we can get seen quickly when accessing emergency health services.
- Where possible, we would like more frequent appointments.

The right to the best possible health means... experiencing personalised care and support



Every time a new healthcare staff member comes to work with a patient it is useful for them to sit and talk to the patient, to identify what measures need to be taken to ensure they can stay healthy.

- We want to be treated as individuals.
- Healthcare staff should talk to us and get to know us.
- We'd like to be asked about our life and treated as a whole person.
- So that our care and support can be personalised, we'd like to be asked what's important to us and what we think will help.



To be given the best healthcare possible, the patients' changing needs and wishes need to be taken into consideration the whole time and be considered a priority.

Services that respect rights make you feel like a real person, not a condition.



The right to the best possible health means... remembering our health is more than our condition

We want advice about all kinds of health issues but sometimes this can get forgotten or overshadowed by our health condition. Getting help with all of our health needs means services remembering that we still have all the same concerns as other young people.



If you have a long-term health condition, that's not the only health issue you have! It's important to remember, we are more than a health condition. We have this as well as all the same health needs other young people have. Don't forget to ask us about this too.

I don't just want information about my condition. I have the same needs as other young people too. I want to be given information about how to stay healthy too.

The right to the best possible health means... being honest and not overprotecting us

I go to the hospital every 4 weeks. I sometimes have these episodes, where me parents go in an absolute panic and they phone the ambulance... . But in the hospital (A&E), the doctors, they talk to my parents, I feel like I'm being ignored. They think it will upset me, but I've been through a lot worse than being told bad information. I've been through a lot worse.

Because even if it's bad news, it's better to know than not know, otherwise you only worry more. We know it, we feel it... we live with it every day.

- We live with our health condition day in and day out so know how it feels better than anyone. Respect our experience and expertise.
- We know our health can be frightening at times, but be honest with us and don't overprotect or patronise us. It's better to know bad news because not knowing is worse than accepting the reality and can make us worry even more.

The right to the best possible health means... getting good information to help us stay healthy

My top tip for better information is to have it in a style that is young people friendly, with bright colours and pictures.

I only usually find out about things if I look on the Internet.

Information to help me stay healthy would be seeing the doctor more regularly.

Things other young people wouldn't have to ask about. Like, I don't know, like how your meds can affect drinking or contraception. They should just tell you that somehow. Too embarrassed to ask.

To me, the right to the best possible health care means to be respected, to be sort of properly looked after and informed about my condition. Being informed about your condition sort of means like facts and how it might affect you and how it's treated, stuff like that.

Information should be about what procedures are really like. Be honest... better to say it might hurt a little bit than say it doesn't.

- Information should be easily available and readily offered so we don't have to search for it ourselves on the Internet.
- Information should engage, be easy to read and accessible.
- Information should also cover issues that we might be too embarrassed to ask about.
- We'd like it to be truthful and realistic.
- As well as generic information leaflets, we also need information that's been adapted for us as individuals covering what we need and want to know. It should be specific to our needs.
- We like information to be available face to face as sometimes we can find out most from talking directly to healthcare staff!

The right to the best possible health means... making healthcare environments age appropriate

- Healthcare environments should be appropriate for different ages of children and young people.
- It should be possible to ensure that wards or waiting rooms look and feel right for children and young people of different ages, with things to watch or do that feel right.

Everything is for little children or adults. Nothing in between. Make wards age appropriate... babies, young children, teenagers.



No more uniforms covered in 'fish or cartoons' when teenagers are around!

The right to the best possible health means... having a good healthcare plan

I want information that is always relative for what I'm in hospital for. When I don't get that help I feel excluded, not a part of what my health plan is.

- We need to be able to understand what's happening with our health condition and care.
- It would be helpful for us to know any signs, symptoms or changes to look out for.
- We should be told who's involved in our care and how they can be contacted.
- We need to know how to manage our health and how others can support us.
- Importantly, we need to be confident that we have the right information about our health.
- We want to know how to make changes to our healthcare and support, if needed.
- We should also know that *we can* make these changes to our own lives and healthcare.

My rights are also respected when I can change my healthcare plan when I feel it's necessary to.

The right to the best possible health means... focusing on our strengths

- Healthcare staff should focus on what we're doing well to manage our own health. This boosts our confidence, making us more comfortable talking to professionals.
- Positivity is important. Don't just tell us what's going badly (or what we're doing wrong) because otherwise we feel frustrated and this can prevent us from being honest or open about how things really are.



You don't want to be dreading going because you know they're gonna say something bad and pick out the tiny little bad things.

The hospital staff could do things better by letting you ask more questions and focusing on the things you do good, not just the things you do bad because they always seem to focus on the bad things more because they need to make them better, but they should also focus on the things you do good, because you want to feel good.

The right to the best possible health means... seeing the same healthcare staff

An example of something that a good health service does is, every time you go to an appointment, if it's regularly, try and use the same doctor. Because if the doctor's more close and you have a better relationship with them then you tend to like, discuss things better with them. And they can recap what happened in the last appointment and see if you're any better.

It helps if you've seen them for a while, they know you, know your illness, know how to react to it.

If you see someone different each appointment, you have to keep recapping what happened in the last appointment or recap on your whole history and illness. It can lengthen appointments and you lose a bit of confidence because you don't know them as well and how they're gonna react.

- We want to trust our healthcare staff.
- We value consistency as seeing different healthcare staff can be frustrating. We don't want to have to repeat our medical history as this can affect our confidence. Seeing the same person is important so that we can learn to trust and open up. It also means healthcare staff can get to know us, our health and our lives (instead of only our condition).

ARTICLES 12 AND 13
THE RIGHT TO BE HEARD:
RESPECT FOR THE VIEWS OF THE CHILD
AND FREEDOM OF EXPRESSION



ARTICLES 12 AND 13

THE RIGHT TO BE HEARD

Children and young people want to be valued as experts about their own lives. They want to be able to make shared decisions about their care alongside health professionals. For this to happen properly there needs to be strong communication – where children and young people are genuinely listened to (not just their parents) and where staff take their time to listen and respond to the detail of what is expressed.

Rights are just the things that happen when you are treated well, when you feel respected and heard.



The right to be heard means... talking with us not about us

- We want you to talk with us, not about us because then we feel listened to.
- Remember that we're the experts in how we feel. If you don't talk to us, you can miss important information about our health or symptoms, even warning signs.
- Our expertise should be respected and this means talking to us as well as our parents. Just speaking to our parents makes us feel excluded from our own care.
- If people discuss us in the third person you should always refer back to us, so that we are always involved in the conversation.

I know my rights are respected in healthcare when my doctor asks me questions, not my parents, because it makes me feel more involved in what I can do with my health care plan.

You might as well not be there if they're just talking to your parents. It makes me feel a bit angry because they're not listening to me.

Rights are just the things that happen when you are treated well, when you feel respected and heard.

My top tip is to listen to the views of the young people because it's them at the end of the day that's got the experience, everyday, of their condition. They don't know our specific needs, so we need to tell them.

Involving young people more... ask them more and speak to them more, instead of their parents, about their condition.

The right to be heard means... being involved in decision about our care

Young people should be involved in their decisions because it's their life. Everything's got to be like, focussed on how they're going to live their life and how it's going to impact.

I should be the one involved in decisions about my health because I'm the one feeling the pain, no one else, no one else knows what I'm feeling, not them.

The right to be heard and listened to is important because, like, everyone has their own opinion on their health and their treatment so they should be included in what decisions are to be made.

It makes you feel like you're a project, well to me, it makes me feel like I'm a project. If there's all these professionals just sat around talking about you and making decisions about what's going to happen to you, then it's, I don't know, it makes me feel like a project.

- We want decisions made with us, not about us.
- Whilst we value the support of our parents and the professionals that help us to make choices, our opinions should always be considered.
- Recognise it's not if but *how* we can get involved in making healthcare decisions. We all know what we think and feel, so no child is too young to be involved in some way in the decision making process.
- Involve us in all decisions about our care, no matter how big or small, because it's our bodies and our lives that are affected and we're the ones who will live with the consequences. Remember whose life is most acutely affected by decisions made.

The right to be heard means... good communication with healthcare staff

- Check in with us to make sure we've understood what you're saying. Don't just ask 'do you understand?' - we'll probably say yes, even if we don't! Ask us to explain what we think you have said or ask us how we would explain it to another young person.
- Avoid jargon or complex words where possible. If you need to use medical terms, explain what it means as this helps us to learn and develop our understanding.
- Show us that you are listening.
- Remember that it's the little things that make the biggest difference and make us feel listened to and heard.
- It's important to focus on who you're actually trying to communicate with.
- Keep it simple. Summarise and make sure things are clear.

My top tip for healthcare people, to show that they are listening to young people, is to talk to them, to summarise in the language that they understand, rather than all this 'blah' type language that we don't really understand.

I know that healthcare staff listen to me because they give me eye contact and answer my questions that's when I know they are listening.

When they talk to my parents instead of me I can't understand what they're saying because my parents are adults and I can't understand the words they're saying. If they were talking to me they would use easier words.

The main part is summarising what you've said and communicating to you. It makes you feel like you're more wanted and you're more wanted to be helped.

If like they re-summarise what you've said and tell it back to you. And that obviously shows they understand or listened.

The right to the be heard means... spending time with us

- Get to know us, not just our condition or treatment as too often we only get spoken to about these things. Ask us about our lives too. It makes us feel like a complete person, and shows us that you really care.
- Make us feel like we are your priority.

My top tip would be for the nurses to take their time to, like, because they have to go to one patient and then the next and they all just run around and they don't stop. They like should have more nurses then, like, if you really need them then they could take their time to sit with you and talk.

I know because, like it might sound strange and stuff, I like sense it, I just know, like, if they don't care you can obviously see the look on their face but if they do care then they like sit with you more and talk to you more and the conversation lasts longer.

The right to the be heard means... talking to us about how things should happen

Understand that being listened to is much more than being asked about what help or support we want or need. We know we're really being heard when health care staff ask us how we want things to be done. This shows you value and respect us.



You can tell when staff are listening to your opinions when they start asking how they could they do something to help you, as opposed to just being told.

I think it's important because they are paying attention to you and to what you want them to do. Sort of communicating what you're going to do and how it's going to go down rather than just saying "this is what is going to happen and this is what we're going to do."



ARTICLES 28 AND 29
THE RIGHT TO EDUCATION



ARTICLES 28 AND 29

THE RIGHT TO EDUCATION

Children and young people know that education is important and want to be able to access this properly when they have long term health conditions. For this to work well, it requires a good level of awareness in the education setting – where support plans are communicated and integrated well, and education staff are confident to give appropriate support. There needs to be flexibility when attendance is affected, and education providers should work creatively so that young people don't fall behind. Being adaptable is particularly important in relation to involvement in sports activities.

Education is essential for everyone; it enables individuals to develop in a multitude of ways and should be available to everyone despite their health status or physical ability. People can often be forgotten with their education if they don't fit into a mainstream school and don't attend full time.



The right to education means... having a named person to talk to

My top tip for school and support would be to have a nurse on standby and someone you can talk to on standby, especially for me in my school.

Schools should maintain as much contact as possible with the child/young person, their carers/parents and the professionals involved to understand what is expected to happen and if there are any changes regarding support needs.

Good support is if someone is taking care of you or you can talk to someone like my head of college or someone who will understand me or what I've got.

- We need someone we can trust and can talk to in school who knows us and understands our health. This reassures us and means there's always someone we can go to if anything changes around our wellbeing, or if we have questions about our education or support.
- Having a named person to talk to makes us feel understood.
- Knowing there is someone in school we can trust makes us feel more secure.

The right to education means... being supported to keep up with our work, if we miss a lot of school

- Keep in touch with us if we are off school for long periods of time so that we still feel like we are part of things and don't fall too far behind.
- Help us from a distance.
- It is important for schools to have plans in place to make sure we can keep up with our work as much as possible. We can miss a lot of school because we are too unwell to go, because we're in hospital or because we have a lot of appointments during school time. We often fall behind if we are in hospital because we don't always get sent work to do. If we are off school for a long time, it can feel as if we have been forgotten about.
- Understand how difficult it is to manage our health and education.

Schools should make sure they send me work if I'm in hospital. They could email it or something, so I can keep up.

Hospital appointments are always in school time.

My health has had a considerable impact on my education due to a significant decrease in my attendance from appointments, inpatient stays and ill health. I had to have a part-time timetable and reduce it even further on several occasions which caused lower attainment grades than anticipated.

The school should have a plan for if the young person is absent, so the work is able to be sent on for completion if the young person is well enough. And if possible offer academic support to enable easier catch up for your return.

The right to education means... an awareness of disability and long term health conditions

- Acknowledge that staff and students often don't understand disability or long term health conditions.
- Increase awareness so that we feel able open up about our health and support needs.
- Help other students to understand and accept that we may need support with our health or learning, and that we're not getting 'special treatment'.
- Work with staff to help them understand the help and support we need, what works well and what needs to be improved across the school.

If people [other young people and teachers] don't understand about my health then they start asking questions about what it is I'm doing and that can be very nerve wracking, because this is like the norm to me, and I have to try and explain myself to other people.

Help other students to understand and accept that we may need support with our health or learning, and that we're not getting 'special treatment'.

In my school, we have meetings with our nurse and the school nurse and some staff, so all the diabetic kids can say what the school does bad and what they can improve on. Just to help us out and the teachers.

[What one thing would you change?] Just the way... the way they address people. In my school, the teachers are always like [points finger repeatedly] and always asking me if I'm ok. I don't know why but I must always seem to look ill!!! Makes me feel like I'm stupid or something. It's just that, I'd like them, maybe, to have a bit of training to tell them, because it annoys me.

The right to education means...
getting the right support in school and involvement
in developing our own support plans

Our school is great. You just have to show 'em. You show 'em what you take and how. Just explain.

The staff need to know about your needs and conditions. A simple way of letting them know what your particular needs are, like... 'This is my health: this is what I need. When this happens: I need this'.

All the staff in the school has a set of key rings that have pictures of the young people with health conditions on. On the other side are bullet points of what symptoms to look out for and what to do if they become unwell. That way, everyone knows what to do and the young people feel safe, wherever they are in school.

I have a care plan. I wrote it with them with my mum. I take it with me everywhere, so people just know what to do, what to look out for. Easy.

- Staff should understand our health, our support needs and what to do if we become unwell.
- We are the experts in our health and should be involved in developing our health support plans in school to make sure that we receive the right support.
- We need an integrated approach.

The right to education means...
getting the right support in school and involvement
in developing our own support plans

Best thing they do at school, is they listen to what I say, and based on what I say and going off my asthma plan... if it's green it means everything's ok, 100%, everything's fine. If I'm amber am so-so, me asthma is affecting us, but not too much, so just look out for symptoms. If it's red call an ambulance, if I'm a little bit worse while I'm waiting use my EpiPen and try and use inhalers. It makes me feel a bit safer, because they know what to do in the situations they're dealing with and they'll know a bit better about how I am at that time and how to deal with the asthma that I have.

I've got a school nurse in my school. Like the school nurse, she could send cards to other teachers to tell them what I am allowed to do, what I'm not allowed to do... like some cards to say what I can and can't do. How they can adapt things for me, so I can join in more.

I am fortunate to have an excellent paediatrician and health care team who regularly communicates with the relevant educational setting to allow me to make the most from my education. In my experience it is useful if NHS staff organise MDT's [multi disciplinary team] and invites a representative from the child or young person's school/ college to attend for part of the meeting.

The right to education means...
making sure we can always get involved in sports and PE



When we do cross country, they ask me friends to watch us when we're running round. If they're watching me, like, they know when something's wrong and can alert someone. Means I can join in.

To help me get involved in sport, for example, in cross country what they do is, if I'm running around the field, obviously the teachers are no way near me and they can only monitor me from where I am in the field. But they get other students like my friends to, erm, look after us and see how I'm doing at the time and keep asking 'are you alright'. If something's wrong they can signal something to the teacher over to apply medication.

The right to education means... making sure we can always get involved in sports and PE

If I can't do sport they always get me involved somehow, whether referring, timing, scoreboard, or just do the warm up.

You can do the scoring or something.

If I'm amber then they say "just sit out when you need. You don't have to tell us, just sit out".

Just sit there and watch everyone else. Sometimes see it as missing out on things other people my age are doing. I'm often the only one who, like, who sits by the side doing nothing.

You have to sit out sometimes and you get bored. You just watch with nothing to do.

- Talk to us about the support we need and let our friends get involved by encouraging them to look out for us.
- Sometimes we can't get fully involved in PE because of our health but you should always find a way to involve us in something, rather than expecting us to sit on the side. There is always something we can do!
- We should be trusted to know how we feel and what we feel capable of.

The right to education means... trusting us about our health

- Respect our experience and understand that we know best about how our health affects us. Trust us about our health and how we manage it.
- Try not to fuss over us! Trust that we'll sit out or take a break if we need to.



The good thing my school does for kids with diabetes is just to understand what they need and if they need to take a break and go out and sort themselves out, they're allowed. It's good because they trust us a lot about what we need.

They're just fine with it. The teachers just let you get on with what you have to do. They understand diabetes. They understand what I need. They just let me sit out if I need to. They trust me... everyone in my class knows too. They just trust me to manage things and to let them know when I need them.

— ARTICLE 31 —
THE RIGHT TO PLAY AND LEISURE



ARTICLE 31

THE RIGHT TO PLAY AND LEISURE

Children and young people want stimulating activities during stays in hospital, with relevant staff who can deliver this properly in an age-appropriate way. Young people also want to get involved in sport and leisure activities in their local communities and want to know staff understand their healthcare needs. Staff need to listen and trust children and young people can make judgements about what leisure activities they can manage.



I get somewhere I can go and have a fun time rather than being bored all day stuck in a room. I can go to a youth room and be free, like watch films and actually talk to people who have similar things, so they know how it is.



The right to play and leisure means... having things to do in hospital

Having access to activities and leisure during hospitals is important because it helps young people to be able to socialise, rather than be isolated all the time, and also helps them make friends while they are in hospital. Then they're not lonely and missing out on things.

The difference the youth service makes when you have long stays in hospital, is that it makes the stay go by faster because if you're just sitting on the ward all the time doing nothing, it just feels like it's dragging on, but you know you can go down to the youth room and play on the Wii and just do what normal young kids do when they're at home... play.

By, like, enabling me to meet other young people, it [the hospital youth service] made me feel more supported, like peer support and like although it's different conditions, they understand more.

- There should be play and youth activities for children and young people of different ages. It's good to have places that we can go in hospitals (play or youth rooms) where we can spend time with other people our age and just do the things that other people our age can.
- It's good when you get support from other young people who are going through similar experiences.
- We don't want to feel bored, lonely or isolated. Having things to do makes long hospital stays less stressful and difficult.

The right to play and leisure means... having youth and leisure staff who understand how to support us

My football club is great. Other people have had asthma, so they understand it. They know what it's like.

Having a health condition can affect access to leisure activities because you have to inform the leader or people in the group about my condition so they can help me in case I get a hypo and avoid that situation.

It would affect me not to take part, because if it's something you really wanted to do then you might be very upset or disappointed because I may really like what's going on.

If I was going to make my coach understand more about asthma, I'd like him to come to one of the asthma meetings, so he could learn more about it.

- We want to feel able to be open and honest about our health and support requirements.
- Staff need to know how to adapt activities so that everyone can take part.
- We should get the support we need to allow us to participate fully and not feel left out or excluded.
- We want reassurance that staff will know what to do if we become unwell.



The right to play and leisure means... trusting that we know about our health, how it affects us and what help we need

- We'd like to be asked what we can do, the support that we need, how we like to be supported and how to adapt activities appropriately. After all, we're the ones who know best about our own health condition and how it affects us.
- We should be trusted when we say we need time out as we know best how we are feeling.



Some of the problems I have at swimming is that, erm... that sometimes when I miss my training he [the coach] thinks that I'm just trying to get out of it and he says "you can't use asthma as an excuse to get out of your swimming". Makes me feel a bit sad, because I feel like he doesn't trust me enough to take my inhalers and things. I think he just thinks I'm out with my friends or something, when I'm actually in bed ill.

SUMMARY

Talking About Rights reveals several recurring themes. Children and young people are clear that knowing about their rights in healthcare for long-term conditions is crucial. They tell us consistently that:

- they need to know and understand what their rights are.
- they want to be properly informed about their condition and healthcare.
- they want to be listened to, and they want staff who take the time to listen properly – to them and not just their parents.
- they don't want to miss out on things because systems are too rigid.

- they need to be a central part of the conversations about their health so that they can share the decision-making about their care.
- the right to the best possible health for young people with long term health conditions is not just limited to health services. This also means respecting young people's right to be heard, understanding how their health affects their education, and their right to play and leisure.

Service providers who value, respect and explicitly implement children's rights as set out in UNCRC will enable the above to happen more easily and provide the best possible healthcare services to children and young people with long term health conditions.

RESOURCES

● ME FIRST

Me first is dedicated to improving communication between children, young people and healthcare professionals and has developed a range of training and online resources. Me first has been developed by Common Room and GOSH, on behalf of Health Education North Central and East London (HENCEL). All of the resources have been co-developed with children, young people and healthcare professionals, and have a strong evidence base in research.

Me first

Children and young people
centred communication

Me first has developed:

- the Me first communication model to support children and young people centred conversations in healthcare.
- a website which contains an interactive Me first communication model to enable you to build your own conversation by adapting the model to your practice; a resource hub, which enables users to share tools, projects and ideas from throughout the UK; and practical advice from children, young people, and healthcare professionals.
- a masterclass for healthcare professionals.



Email

info@mefirst.org.uk



Link

www.mefirst.org.uk

RESOURCES



● COUNCIL FOR DISABLED CHILDREN

Children and young people's health rights in England: shared messages

In signing and ratifying the UN Convention on the Rights of the Child the UK Government has committed to realising its articles through domestic legislation and policies. This report reviews the NHS constitution and three key documents (see pages 5 and 6) on children and young people's health to establish core messages on what children and young people should expect from health services in England. It provides a comparison of these documents in terms of their coverage of key issues informed by our research with children and young people into their understanding of the NHS Constitution and their rights when using the NHS.



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* www.councilfordisabledchildren.org.uk/resources/children-and-young-people-s-health-rights-in-england-shared-messages

Children and young people's views on the NHS Constitution: engaging themes.

National Children's Bureau and the Council for Disabled Children have been speaking to children and young people about the NHS Constitution.

Building on a short consultation event in 2010, we wanted to find out what children and young people thought about the NHS Constitution and how it related to their experiences of NHS care. This document presents children and young people's experiences of using NHS services and their views on how the NHS Constitution can be improved.



Link

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* www.councilfordisabledchildren.org.uk/resources/children-and-young-people-s-views-on-the-nhs-constitution-engaging-themes

RESOURCES

● COMMON ROOM

Common Room promotes shared decision-making, person centred practice, and the views and expertise of children and young people with lived experience across disability, health, and mental health. We work in partnership with young people to ensure they:

- are actively involved in decisions about their lives, treatment, support and services.
- are equal partners in research, service development, quality improvement and policy programmes.
- have a voice about social, policy and practice issues that affect their lives.

COMMON ROOM



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www.commonroom.uk.com

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