



**Children & young
people's health
rights in England:
Shared Messages**



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The United Nations Convention on the Rights of the Child Article 24 sets out children and young people’s right to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. The Government shall strive to ensure that no child is deprived of his or her right of access to such health care services.

United Nations Convention on the Rights of the Child (1989) (UNCRC)
www.unicef.org/crc/files/Rights_overview.pdf

Introduction

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.

The groups we spoke to included:

- Children and young people with learning disabilities
- Children and young people with long term health conditions with extensive experience of the health system
- Children and young people with mental health issues
- Children and young people with experience of local authority care

During this research we found that the children and young people only had a limited understanding that they, as patients and members of the public, had any rights when using NHS services.

We also found that the majority of children and young people had experiences of the NHS that did not meet their expectations and they identified many examples of where they would like to see improvements.

The issues they raised can be grouped into eight themes, which we have used to structure our analysis:

- **Availability and access**
- **Clinical quality**
- **Communication, confidentiality and respect**
- **Complaints**
- **Individual involvement in decisions**
- **Collective involvement**
- **Integration and transition**
- **Wellbeing and prevention**

Under each of these themes we have constructed a number of statements which incorporate the relevant rights, commitments and pledges from the four documents we reviewed. We then set out in more detail the key things each of the documents say about these issues. A summary table of the statements and their coverage in each document is included in appendix B.

To inform further work on raising awareness of children's health rights, we also undertook a survey of front line professionals, including asking them about awareness and influence of the four documents. The results of this are summarised in appendix A.

The four documents we looked at



NHS Constitution

The Constitution brings together the existing legal rights and responsibilities of patients, the public and staff in relation to any service that is funded by the NHS.

The Constitution was first published in 2009 and its legal status was strengthened by the Health and Social Care Act 2012. Every part of the NHS now has a duty to take account of the Constitution and promote and raise awareness of it to those who use health services. This means that it has the potential to be a powerful tool for raising children and young people's rights as a priority issue within the new NHS system.

It is important to note that the Constitution does not explicitly mention children and young people but we have taken all the rights as applying to children and young people. However, the specific circumstances children and young people face mean there may be additional issues that mean the implications of a right are not the same as for an adult patient.

www.gov.uk/government/publications/the-nhs-constitution-for-england



You're Welcome

Quality criteria for young people friendly health services

The You're Welcome quality criteria provide a set of non-mandatory standards for delivering young person-friendly health services for 14-19 year-olds in England. They are designed to be used by health services themselves to assess how well their provision meets the needs and preferences of young people. Services that meet the criteria are awarded You're Welcome status and are entitled to display the You're Welcome quality mark.

Quality assurance was provided by the Department of Health until 2010 when this was devolved to local health agencies. The latest version of the quality standards was published in 2011.

www.gov.uk/government/publications/quality-criteria-for-young-people-friendly-health-services

The four documents we looked at — *continued*

M

Children and Young People’s Manifesto for Health and Wellbeing

The Chief Medical Officer’s report, *Prevention Pays – Our Children Deserve Better* (published in 2013) included a chapter on the voices of children and young people. This explored what children and young people have said about health, based on a literature review, drawing on the work of NCB, CDC and others, and four additional focus groups/workshops of children and young people, which helped triangulate the issues arising from the literature review. ‘A Children

and Young People’s Manifesto for Health and Wellbeing’ forms the conclusion of the chapter based on this. The report suggested that this would be useful for building on *You’re Welcome*.

[www.gov.uk/government/publications/ chief-medical-officers-annual-report- 2012-our-children-deserve-better- prevention-pays](http://www.gov.uk/government/publications/chief-medical-officers-annual-report-2012-our-children-deserve-better-prevention-pays)

P

Better health outcomes for children and young people Pledge

The better health outcomes for children and young people ‘Pledge’ is part of the response from the Department of Health to the recommendations of the Children and Young People’s Health Outcomes Forums. The Pledge sets out 5 ‘Shared Ambitions’ and 5 ‘Commitments’ to improve health outcomes for children and young people that a wide range of NHS organisations and professional bodies have signed up to.

[www.gov.uk/government/publications/ national-pledge-to-improve-children-s- health-and-reduce-child-deaths](http://www.gov.uk/government/publications/national-pledge-to-improve-children-s-health-and-reduce-child-deaths)

These icons indicate which of the documents support the statement

C

NHS Constitution

YW

You’re Welcome quality criteria

M

Children and Young People’s Manifesto for Health and Wellbeing

P

Better health outcomes for children and young people ‘Pledge’

“I got told that it would take six to eight weeks when I’d already waited nine weeks for a primary care referral just to get, the primary care was just a triage and then to get referred on from that, so overall from realising I wanted to get re-referred it’s like, it’s going to be sixteen weeks, just way too long. And he said, oh, I’ll call you with updates, and no updates are coming.”

One Availability & access

C

Decisions about commissioning should be based on assessment of children and young people's needs

The Constitution sets out the right to have the NHS to assess the health requirements of your community and to commission and put in place the services to meet those needs as considered necessary. This includes public health services.

It stresses that local commissioning decisions about funding drugs and treatments should be made rationally following a proper consideration of the evidence. If the NHS decides not to fund a drug or treatment that children and young people or their doctor thinks would be right for them then they must explain that decision.

YW**M**

Children and young people are provided with information on how to access services

Children and young people say in the Manifesto that they want services to provide child-friendly health information in places where they can find it easily such as schools, clubs and on the internet. They also suggest a directory of child and young person friendly services that they can access themselves and health professionals can use to signpost them.

You're Welcome includes provisions that services should provide information

including leaflets for young people on what they provide, how to access the service and what to expect when they do access the service. Information should be made available in a variety of languages and formats, in forms accessible to young people with disabilities in accordance with equality legislation and in the languages that are used by young people in the community. It should be kept up to date and include relevant information about other services in the area.

C**YW****M****P**

Children and young people have timely access to services

Children and young people say in the Manifesto that they want access to age appropriate services when they need them, and for services to have flexible opening times, including weekends and early evenings.

Through the Pledge health agencies have stated their ambition that services for children and young people are delivered at the right time.

The NHS Constitution includes a right to access to services within waiting times specified in the handbook.

You're Welcome includes a provision that young people can use the service at times convenient to them where possible.

YW**M****P**

Service settings and their location provide for independent and non-stigmatising access for children and young people

Children and young people say in the Manifesto that they want access to age appropriate services where they need them, and in convenient, non-stigmatising locations, close to home.

Health agencies have stated their ambition that services for children and young people are delivered in the right place.

You're Welcome includes provisions that services are easily accessible for young people with any physical or sensory impairment and that where there is a choice about service location, the service is accessible to young people by public transport.

YW**M****P**

There is provision to ensure access to services for children with complex needs or access challenges

Children and young people have indicated in the Manifesto their concern that those with mental health issues are able to access services in a timely manner.

Health agencies have pledged to support and protect the most vulnerable, including by providing better support to the groups that have the worst health outcomes. (Pledge commitment)

You're Welcome includes provisions that services are provided for socially excluded and marginalised young people, listing several examples of groups of children who this might apply to.

C**YW**

Children and young people will not be turned away from services unreasonably

The NHS Constitution includes a right to access NHS services and states that people will not be refused access on unreasonable grounds. It also states the right not to be unlawfully discriminated against in the provision of NHS services on the grounds of protected characteristics.

You're Welcome includes provision that sexual health services will see young people for advice and contraception who are not ordinarily registered with them.

Availability & access Observations

The Constitution sets out the fundamental rights of all patients to have their needs taken into account through the commissioning of NHS services to ensure that the appropriate services are in place to meet their needs.

While the Pledge and You're Welcome both contain commitments to put in place services for disadvantaged children and young people and those with long term health conditions, the needs of children and young people, especially those from disadvantaged groups are often not fully represented in the commissioning process.

There needs to be a clear relationship between the commissioning of available services and collective involvement in decision making (see section 5) to ensure that the children and young people's needs and their views are adequately represented and the appropriate services are put in place. The availability of population-level data is also a challenge for consideration of children's needs in commissioning.

While You're Welcome makes clear demands on the accessibility of information about accessing services, consideration will need to be given to what the information resources will look like and how they are deployed, given the range of services children and young people are likely to use.

Specified waiting times (currently 18 weeks or 2 weeks if cancer is suspected) do not yet apply to psychological therapy, which children and young people have reported trouble accessing. Neither do they apply to public health services commissioned by local authorities (such as sexual health services). In practice, the location and opening times of a service will also be factors in how long it takes to access a service.

The Pledge discusses access in terms of delivering services 'in the right time, at the right place.' This quite generic statement of intent may describe a subjective clinical judgment about what is 'right' rather than seeking to offer any entitlement to access services within particular timeframes, geographic areas or particular measure of convenience.

Further reading

RCGP with RCPCH and RCN (2013), *Commissioning a good child health service*

www.rcgp.org.uk/~media/Files/CIRC/Child-and-Adolescent-Health/RCGP-Child-Health-Modelling-Task-Group-April-2013.ashx

Guidance on Reasonable Adjustments under Equality Act 2010

www.equalityhumanrights.com/private-and-public-sector-guidance/organisations-and-businesses/duty-make-reasonable-adjustments-remove-barriers-disabled-people

Forthcoming: Statutory Guidance on promoting the health of looked after children

“Well you’re not going to get anywhere if it’s low quality, it’s just going to make you worse and it’s just going to end up costing more.”

Two Clinical quality

C**YW****M****P**

Staff have appropriate training in the care of children and young people

Children and young people say in the Manifesto that they want child-friendly care from people they know and trust and who treat them with respect.

Health agencies have pledged that services will be delivered by a properly planned, educated and trained workforce.

The NHS Constitution includes a right to be treated with a professional standard of care, by appropriately qualified and experienced staff.

You're Welcome includes provisions that:

- All staff who are likely to come into contact with young people receive appropriate training on understanding, engaging and communicating with young people
- All staff receive appropriate training in equality and human rights issues for them to be able to engage with confidence with a range of young people
- Appropriate staff members receive training, supervision and relevant appraisal to ensure that they are competent to: Discuss necessary and relevant health issues with young people and understand the health needs of young people in the context of people's lives and relationships; work with parents/carers/family and friends where appropriate in culturally appropriate ways; and make appropriate referrals when necessary
- Appropriate mental health staff receive appraisal and training to ensure that they can talk to young people about mental health issues, know about treatment and support options and are able to respond to different therapeutic needs as they relate to culture and identity
- Young women with unplanned pregnancies have access to advice on all options from someone who does not have conscientious objections.

C**YW****M**

Children and young people are provided with treatment that is based on clinical need, age appropriate and follows any relevant NICE recommendations

Having age appropriate services and treatments available was an issue for children and young people in the Manifesto.

The NHS Constitution includes a right to drugs and treatments that have been recommended by NICE for use in the NHS, if your doctor says they are clinically appropriate for you.

In its sections on mental health and sexual health, You're Welcome stresses the importance of treatments being delivered by staff who receive appropriate training, appraisal and support to work with children and young people.

C

Treatment and settings are safe

YW

The NHS Constitution includes a right to be treated by an organisation that meets the required standards of safety.

You're Welcome includes a provision that care is delivered in a safe environment.

P

Health agencies have pledged that services will be safe.

YW

Settings are designed with children and young people's comfort in mind

M

Young people say in the Manifesto that they want young people friendly care and to have hospital wards specifically for teenagers and young adults.

You're Welcome includes provision that care is delivered in a suitable, young person-friendly environment.

YW

Pain is managed appropriately

You're Welcome includes provisions that:

- Pain relief is an explicit part of young people's care and staff are trained in pain management

- The effects of analgesia are taken into account when considering young people's cognitive ability
 - Young people's dignity is maintained during treatment and care.
-

YW

Assessment and care planning considers the needs of the whole child

You're Welcome includes provisions that:

- Staff members can discuss health issues with young people in the context of their lives and relationships and work with their families and friends in culturally appropriate way
- The care and support of young people with complex needs should include assessment of physical, psychological and emotional needs in the context of their cognitive ability and chronological age

- Appropriate mental health staff receive appraisal and training to ensure that they can respond to different therapeutic needs as they relate to culture and identity.
-

Clinical quality Observations

This is a broad theme covering the type of treatment and care that children and young people receive and the setting in which it is provided. Ensuring that treatments and medications are age appropriate is a key issue, as is providing the right setting for treatment to ensure children and young people are comfortable. Training of the workforce will impact on these issues, as well as the other themes in this analysis.

Where the NHS Constitution discusses staff being appropriately trained this refers to the health professions being governed by their professional bodies and regulators (as explained by the Constitution Handbook). This potentially underplays the political aspect of decisions about workforce training such as how much money is invested in the training of various professions.

There may be a role for Health Education England and Local Education and Training Boards in profiling and enhancing locally the competency and confidence of the local NHS workforce.

Responsibility for clinical quality and patient safety sits mainly with the Care Quality Commission, who should take into account the standards of children and young people specific care.

Under section 131A of the Mental Health Act 1983 hospitals must provide age appropriate accommodation for children and young people aged under 18.

Further reading

NICE Quality Standards – these include children and young people-specific quality standards relating to cancer, depression, epilepsy, eczema and conduct disorder.

www.nice.org.uk/guidance/published?type=QS

RCGP with RCPCH and RCN (2013) *Commissioning a good child health service*

www.rcgp.org.uk/~media/Files/CIRC/Child-and-Adolescent-Health/RCGP-Child-Health-Modelling-Task-Group-April-2013.ashx

“Because doctors do speak to you in a horrible way, even if a doctor’s talking to another doctor in a horrible way and then that doctor goes and treats someone and they take it out on their patients.”

“They can be like, we have people with illnesses, we’ve got people actually dying here, and it’s like, you’re wasting my time, and that’s really horrible.”

Three Communication, confidentiality & respect

C**YW**

Professionals will communicate with children and young people in an appropriate way that values them and ensures they understand what is being communicated

The Constitution pledges that the NHS will always involve children and young people in discussions about planning their care and will offer a written record of what is agreed if they want one. The NHS also pledges that staff will encourage and welcome feedback on health and care experiences and use it to improve services.

You're Welcome sets out what this looks like in more practical terms, setting out provisions to ensure that:

- Care is delivered in a safe, suitable and young people friendly environment. Young people are not asked any potentially sensitive questions where they may be overheard for example in the reception, waiting areas, ward environment
- All staff routinely explain who they are, and what they/the service can and cannot provide to help young people. The service considers the physical and cognitive ability of the young people and takes into account the effects of sedation and analgesia and mental health state.

To support staff to feel comfortable communicating with children and young people in an appropriate way You're Welcome also includes provision that:

- Services should ensure that all staff who are likely to come into contact with young people receive appropriate training on understanding, engaging and communicating with young people. All staff receive appropriate training in equality and human rights issues for them to be able to engage with a range of young people and promote positive attitudes and values.
- Appropriate staff members receive training, supervision and relevant appraisal to ensure that they are competent to manage sensitive and/or difficult consultations
- Appropriate [sexual health] staff receive training, supervision and appraisal to ensure that they are able to talk to young people about sexual health issues, including delaying sex, and are knowledgeable about the full range of contraceptive options, promoting positive sexual health, preventing pregnancy and STIs.

C**M**

All information should be provided in a way that can be clearly understood by children and young people to help them take part in decision making

In the Manifesto children and young people said they want to be informed and have a say in decisions about their care, and made recommendations about how this could be achieved:

- Receiving a printout or email from the doctor after their appointments with a summary of the key information discussed
- Policy makers ensuring that they provide information about health policies that are applicable to children and young people in child-friendly formats and places where it can be found easily, such as through social media.

The NHS Constitution sets a clear right to be given information about the test and treatment options available, what they involve and their risks and benefits.

The Constitution also makes the pledge to offer easily accessible, reliable and relevant information in a form that children and young people can understand, and support to use it. This will include information on the range and quality of clinical services where there is robust and accurate information available.

C**YW**

Children and young people have control over information

The Constitution sets out the right for children and young people to be informed about how their information is used and to request that their confidential information is not used beyond their own care and treatment and if their wishes cannot be followed, to be told the reasons including the legal basis.

The Constitution also pledges that where identifiable information has to be used, to give children and young people the chance to object wherever possible.

The Constitution sets out a right to access their health records and to have any factual inaccuracies corrected.

C**YW****M**

Children and young people's privacy and confidentiality is taken seriously by professionals and services

Privacy and confidentiality are important elements of the Manifesto, with children and young people saying they want healthcare and social care professionals and teachers showing due regard for children and young people's rights to privacy and confidentiality. They also want policy makers, health professionals and teachers to help children and young people to understand their rights to confidentiality.

The Constitution contains a right to privacy and confidentiality and to expect the NHS to keep confidential information safe and secure.

You're Welcome includes a number of principles regarding privacy and confidentiality.

- Services will have a confidentiality policy that staff follow that includes who else has access to any information that the young person

shares with the service, circumstances under which information may be disclosed or shared and how staff will work with parents and carers whilst respecting children and young people's confidentiality

- This confidentiality policy will be actively promoted to children and young people with information making clear young people's entitlement to confidentiality and any limitations to confidentiality with regard to safeguarding
- Children and young people will be able to attend consultations on their own without the involvement of a parent or carer
- Members of staff routinely receive inter-disciplinary training on the issues of confidentiality and consent and issues pertaining to seeing young people without a parent/ carer present.

C**YW****M**

Children and young people are treated with dignity and respect

Being treated with dignity and respect is key priority for children and young people, and the Manifesto reflects this, saying that children and young people want to have personalised, child-friendly care from people they know and trust and who treat them with respect.

The Constitution enshrines the right for children and young people to be treated with dignity and respect, in accordance with their human rights.

You're Welcome includes provision that young people's privacy and dignity are maintained during discussion, examination, treatment and care.

Communication, confidentiality & respect Observations

Communication is a key area for children and young people and the Constitution includes a right that patients will be provided with information that they can understand. However the commitment to involving them in discussions about their care is not a right but is a weaker 'pledge'. Recognition of the importance of ensuring health professionals have the skills required to communicate with children and young people, especially those with additional needs, and involve them in discussions about their health is only directly referred to in the You're Welcome principles.

The NHS Constitution does not address the issue of young people's consent and parental involvement relating to under 18s and under 16s. This is a key issue raised by young people as one where they do not understand what they should expect from the NHS, and impacts on their confidence when using services.

You're Welcome highlights the importance of services explaining confidentiality policies to children and young people, but it also does not explicitly set out the nature of rights relating confidentiality for under 18s and their parents.

Further reading

Department of Health (2001), *Consent – what you have a right to expect: A guide for parents*
www.nhs.uk/NHSEngland/AboutNHSservices/Documents/Consent_aguideforparentsDH_4117353.pdf

Health and Social Care Information Centre (2013), *A guide to confidentiality in health and social care*

www.hscic.gov.uk/confguideorg

“As long as we have the right information I think we should be able to choose... we should be able to decide, we’re the patient.”

“They need to give you time and explain. And unless you’re two years old or something or actually at risk to yourself obviously or something like that I don’t see why you shouldn’t be able to make your own decisions.”

Four Individual involvement in decisions

C**YW****M****P**

Children and young people are supported to take part in decisions about their own care and support

For children and young people, the extent to which they are supported to be involved in discussions and choices made about their treatment and support is a major issue, and this importance is clearly articulated in the Manifesto.

The Constitution contains a number of rights that relate to taking part in decision making, with a central right to be involved in discussions and decisions about health and care, including end of life care, and to be given information to do this. Where appropriate this right includes family and carers, which is an important aspect for children and young people and the Constitution also pledges that the NHS will work in partnership with them, their family, carers and representatives.

The Better Health Outcomes Pledge contains an ambition that children, young people and their families will be at the heart of decision-making, with the health outcomes that matter most to them taking priority.

You're Welcome includes provision for appropriate staff members to receive training, supervision and relevant appraisal to ensure that they are competent to support young people in making their own informed choices.

You're Welcome also includes provisions that address specific issues relating to children and young people's involvement in decision making regarding sexual health services, mental health services and care related to pain relief. This includes:

- Ensuring children and young people are able to make informed decision about their pain management and where possible the young person's views are central to the decisions about their pain relief
- All appropriate mental health staff routinely discuss choices with young people and are flexible about involving other people in the assessment and treatment process, ensuring children and young people understand what can be achieved without parental or family involvement wherever this is considered to be therapeutically beneficial
- Even when assertive or compulsory treatment is needed children and young people should always be offered appropriate information and advice about what choices can be made available and which treatment the young person would like to receive.

C**YW****M**

Children and young people will be enabled to give informed consent to their treatment

The Manifesto highlights how important consent is to children and young people, calling for health professionals to take time to ensure that children and young people can give informed consent, including for procedures carried out on them, when appropriate.

The Constitution contains the right to accept or refuse treatment that is offered and not to be given any

physical examination or treatment unless valid consent has been given. If someone does not have the capacity to give consent it must be obtained from a person legally able to act on their behalf, or the treatment must be in their best interests.

You're Welcome specifies that staff in sexual health and mental health services will be able to recognise and facilitate informed consent.

C**YW**

Children and young people will be provided with appropriate information to make informed decisions about treatment and consent

Having appropriate information is a vital element of being able to take part in decisions about care and give consent.

The Constitution sets out the commitment for patients to receive accessible, reliable and relevant information in a form they can understand, and support to use it to participate fully in healthcare decisions.

This will include information on the range and quality of clinical services where there is robust and accurate information available

You're Welcome includes provision for mental health services to provide advice and information to help children and young people and their families take part in informed decision making.

C

Children and young people are able to make choices about the services commissioned by the NHS

The Constitution sets out a right to make choices about the services commissioned by NHS bodies and to information to support these choices. The options available will develop over time and depend on their individual needs. The Constitution also pledges to inform you about the healthcare services available to you, locally and nationally. This refers to an individual's choice of provider once they are referred for treatment.

Individual involvement in decisions

Observations

The NHS Constitution sets out the rights patients have to be involved in decision making about their health and sets out the extent of patients' rights to control the information the NHS holds about them. These rights may be extended to family and carers but the NHS Constitution does not demarcate the relationship between children, young people and their parents in the decision making process, and how this evolves as they get older.

You're Welcome provides more clarity in this area with the principles requiring services to explain to children and young people how they can be involved in the decision making process, both with and without their parents and carers.

The Constitution, Manifesto and You're Welcome all stress the importance of informed consent, but the Constitution does not specifically address the issue of consent for children and young people between 16 and 18 relating to the Mental Capacity Act 2005, or Frazer/Gillick Competent children aged under 16.

You're Welcome sets out good practice for mental health services where they are providing care without consent under the Mental Health Act 1983, but this does not cover parental involvement in these decisions.

Further reading

Mental Capacity Act 2005

www.legislation.gov.uk/ukpga/2005/9/contents

General Medical Council (2007), *0-18 years: guidance for all doctors*

www.gmc-uk.org/guidance/ethical_guidance/children_guidance_index.asp

Council for Disabled Children (2011), *Managing My Way*

www.healthwatch.co.uk/complaints/guides

“...we all had changes that we wanted to make, and we couldn’t improve them as individuals but if we all came together we could, actually.”

Five Collective involvement

C**YW****P**

Children and young people are involved in the routine planning of health services

Health agencies have pledged that children, young people and their families will be at the heart of decision-making, with the health outcomes that matter most to them taking priority.

The NHS Constitution sets out a right to be involved, directly or through representatives, in the planning of healthcare services commissioned by NHS bodies.

You're Welcome includes provision that young people are routinely consulted in relation to current services and that processes are in place to ensure that young people's views are included in governance service design and development.

C**YW****P**

Children and young people are consulted on any proposed changes to services

Health agencies have pledged that children, young people and their families will be at the heart of decision-making, with the health outcomes that matter most to them taking priority.

The NHS Constitution sets out a right to be involved, directly or through representatives, in the development and consideration of proposals for changes in the way those services

are provided, and in decisions to be made affecting the operation of those services.

You're Welcome includes provision that young people are routinely consulted in relation to relevant new developments.

C

Children and young people are given the information and support they need to influence and scrutinise the planning and delivery of services

The NHS Constitution includes a pledge to provide the public with the information and support they need to influence and scrutinise the planning and delivery of services.

YW

Children and young people are involved in evaluation of services

You're Welcome includes provision that young people are routinely involved in reviewing local service provision against the quality criteria it sets out.

YW

Children and young people are included in patient surveys

M

Young people say in the Manifesto that they want to be included in more national surveys about health, and that particular attention should be paid to hard-to-reach groups and children with disabilities.

You're Welcome includes provision that young people are included in patient satisfaction surveys.

C

There are effective provider-level feedback mechanisms

YW

The NHS Constitution includes a pledge to encourage and welcome feedback on health and care experiences and use this to improve services.

You're Welcome includes provision that services invite and encourage all clients to give their opinions of the service offered and whether it met their needs and that these are reviewed and acted on as appropriate.

M

Lessons from the views and experiences of children and young people collected in the past are shared, built on and acted on

Children and Young People say in the Manifesto that they want to have the opportunity to learn from the past experiences of other young people, and health professionals, service providers and commissioners to listen seriously to and learn from the past experiences of other young people.

Collective involvement Observations

The Pledge discusses children, young people and their families as one entity and says that they will be 'at the heart' of decisions which does not give a clear indication of the level of participation envisaged.

The NHS Constitution and You're Welcome use different language in discussing collective involvement. While the Constitution talks of a right to be 'involved' in decisions, You're Welcome talks about 'consulting' young people. 'Involve' is generally considered a stronger term, as it encapsulates patient and public input from an early stage in the process (rather than commenting on a single option, the core aspects of which have already been decided).

You're Welcome is perhaps less clear on empowering young people to have an impact at a strategic level, through, for example, providing information (as pledged in the Constitution) or enabling the sharing of experiences between children and young people and across the NHS (as suggested by the Manifesto).

While You're Welcome and the Manifesto call for children to be included in patient surveys, the choice of surveys deployed in services are largely determined by nationally set reporting requirements and Outcomes Frameworks, which tend to exclude children.

Further reading

NHS England (2013) *Transforming Participation in Health and Care* (This is official guidance from NHS England on the range of patient and public participation duties on commissioners introduced by the Health and Social Care Act 2012)

www.england.nhs.uk/ourwork/patients/participation

Office of the Children's Commissioner for England (2013), *We would like to make a change – Children and young people's participation in strategic health decision-making*

www.childrenscommissioner.gov.uk/content/publications/content_655

“I have made a complaint, it was horrible... I think they were just making excuses for her, that was how I felt.”

“...I don't think it's signposted enough. There's a lot to do, you've got to search where to make a complaint, you're not told.”

Six **Complaints**

C**YW****M**

Children and young people and their families have the information and support they need to make complaints and are kept informed throughout the process

Children and young people say in the Manifesto that they want service providers and commissioners to ensure that children and young people are told how to make complaints about their care and are supported through the process.

The NHS Constitution sets out rights to:

- Have complaints acknowledged within 3 working days
- Discuss the manner in which the complaint is to be handled, and

to know the period within which the investigation is likely to be completed and the response sent.

It also includes a pledge that people will receive appropriate support throughout the handling of the complaint

You're Welcome includes provision that services provide information on how to make comments, compliments or complaints about the service in a variety of languages and formats including leaflets for young people.

C

If a child or young person or their family makes a complaint they are treated with respect

The NHS Constitution sets out a right to have complaints investigated properly. It also includes a pledge to ensure that people are treated with

courtesy and that the fact that they have complained will not adversely affect their future treatment.

C

There are mechanisms to complain or appeal to a third party

The NHS Constitution sets out rights to:

- Make a claim for judicial review if you think you have been directly affected by an unlawful act or decision of an NHS body or local authority
- Take your complaint to the independent Parliamentary and Health Service Ombudsman or Local Government Ombudsman, if you are not satisfied with the way your complaint has been dealt with by the NHS.

C

An appropriate response is received to the complaint

The NHS Constitution sets out a right to compensation where you have been harmed by negligent treatment. It also includes pledges to ensure that:

- When mistakes happen or if you are harmed while receiving health care you receive an appropriate explanation and apology, delivered

with sensitivity and recognition of the trauma you have experienced, and know that lessons will be learned to help avoid a similar incident occurring again

- The organisation learns lessons from complaints and claims and uses these to improve NHS services.

Complaints Observations

The NHS Constitution right to discuss a complaint and pledge of support does not explicitly include information on how to initiate a complaint. Conversely, You're Welcome does not specify the manner in which complaints are to be dealt with or any support beyond information on how to complain.

Being able to complain to someone not involved in the care at issue is particularly important given that it is only a pledge (not a right) for the fact that a complaint has been made to not adversely affect your care. The Handbook to the NHS Constitution explains that the Parliamentary and Health Services Ombudsman does not generally investigate cases where NHS complaints processes have not already been exhausted. The right to complain,

however, does include a right to complain to a commissioner (who will be one step removed from the care). It is not clear what role commissioners will have in a complaint if they see it as concerning the behaviour of a provider or professional in an individual case (as opposed to concerning their strategic role as a commissioner).

Advocacy services are not mentioned.

The Children's Commissioner for England has drawn up eight Common Principles for a Child Friendly Complaints Process, informed by research into children and young people's experience of making complaints in the health service.

Further reading

Department of Health (2013), *Handbook to the NHS Constitution* pp78-85

www.gov.uk/government/publications/the-nhs-constitution-for-england

Office of the Children's Commissioner for England (2013), *Common Principles for a Child Friendly Complaints Process*

www.childrenscommissioner.gov.uk/content/press_release/content_517

Ann Clwyd MP and Professor Tricia Hart (2013), *A Review of the NHS Hospitals Complaints System Putting Patients Back in the Picture*

www.gov.uk/government/publications/nhs-hospitals-complaints-system-review

Healthwatch England and Citizen's Advice (2013), *Consumer guides to making complaints about health and social care*

www.healthwatch.co.uk/complaints/guides

“It’s partnership working, isn’t it, it’s both the hospital and social services, really working together.”

“I was on a paediatric ward and I was supposed to be being discharged because I was fine and the doctor came over and was like, we’re really sorry but someone forgot to ring up CAMHS to check you could be discharged and let them know and you’re going to have to stay in overnight.”

Seven **Integration** **& transition**

YW**M****P**

Children and young people will experience integrated care

The integration of care across different services is highlighted as an issue in the Manifesto with children and young people saying that they wanted health professionals, service providers and commissioners communicating and working together to ensure that services are co-ordinated and integrated, so that children and young people are not 'passed around different systems' and do not have to keep 'repeating their story' to each new health worker they meet.

The Pledge contains an ambition that there will be clear leadership, accountability and assurance and organisations will work in partnership for the benefit of children and young people.

You're Welcome contains the provisions that the care and support of young people with complex needs are considered in the context of their cognitive ability and chronological age. This should include assessment of physical, psychological and emotional needs.

C**YW****P**

Services will work together to make the transition in and out of services, and between different providers as smooth as possible

The Constitution pledges that the NHS will make the transition for children and young people as smooth as possible when they are referred between services, and then put them and their family and carers at the centre of decisions that affect them.

The You're Welcome standards include provision that where possible, other relevant services for young people are co-located within the service.

Where this is not the case, staff will be familiar with local service provision and arrangements for referral and children and young people will be provided with information about other local services.

The health system Pledge states that services will be integrated and care will be coordinated around the individual.

M

Children and young people looked after by the local authority will receive specific support to manage the transition between services

The Manifesto highlights the additional needs of looked after children and young people when moving between services. To do this health and social care professionals should ensure that looked after children have the

preparation they need for discharge from services and services support looked after children to be more involved in their case reviews.

YW**P**

Children and young people will be supported in making the transition from children's to adult services

In the Manifesto children and young people said that being supported through the transition to adult health and social care services was a significant issue for them. The manifesto outlines this as GPs and other health professionals working in partnership with the young person and their families or carers, where appropriate, to manage the transition process over a period of time and at a pace that is appropriate for the individual, with information, continuity of care and clear handover to adult services

“Transition services are the poorest part, especially within mental health, I think they fall down extremely badly and there’s a really big inequality across the country of what happens. And I know a big thing is that people say they’re not given any information they’ve just been told, you’re off to another service.”

The health system pledge sets out an objective/commitment that Services will be integrated and care will be coordinated around the individual, with an optimal experience of transition to adult services for those young people who require ongoing health and care in adult life.

You're Welcome sets out 3 principles relating to the transition to adulthood:

- That services have a clear procedure to prepare young people for the transition from health services designed for children and young people to adult health services, consistent with Department of Health guidance and specific attention is given to the needs of young people with long-term health needs
- Appropriate staff members are trained to help young people, and their parents or carers, with the transition to adult services from the age of 12 onwards. All young people with ongoing needs have an individual transition plan. This will usually include a named key-worker for each young person who will provide continuity during the transition process.
- The service provides publicity material specifically outlining the transition to adult services. This material is attractive to young people and is presented in a way that is young people-friendly.

Integration & transition Observations

The Manifesto, the Pledge and You're Welcome all highlight transition to adult services as a particularly important issue, especially for disadvantaged groups, such as those with long term health conditions and children and young people in local authority care.

Despite the prominence given to transition in the three documents there is no right in the Constitution to integrated care or to be supported when transitioning between children's and adult services.

There is a pledge to support transition between services, but this does not specify the transition to adult services. Along with wellbeing and prevention, integration appears to be one of the issues least reflected in the Constitution, but is perhaps the more significant of the two, owing to the Constitution's limited remit in public health and outside of NHS services.

Further reading

Forthcoming – National Voices (2015), *A Narrative for person centred coordinated care: children and young people with complex lives*

Care Quality Commission (2014), *From the pond into the sea: Children's transition to adult health services*

www.cqc.org.uk/sites/default/files/CQC_Transition_Report.pdf

Royal College of Nursing (2013), *Lost in Transition*

www.rcn.org.uk/___data/assets/pdf_file/0010/157879/003227_WEB.pdf

“I think they push a lot more in inpatient care rather than in the community.”

Eight Wellbeing & prevention

C**YW****P**

Children and young people's contact with health services is used as an opportunity to promote wellbeing and healthy lifestyles

Health agencies have pledged to help children and young people and their families to prioritise healthy behaviour.

The NHS Constitution states that staff should aim to take every appropriate opportunity to encourage and support patients to improve their health and wellbeing.

You're Welcome includes provision that as appropriate, consultations routinely promote healthy lifestyles, including:

- Smoking cessation
- Healthy eating and weight management
- Alcohol misuse
- Long term health needs
- Substance misuse
- Mental health or emotional health and psychological wellbeing concerns
- Sexual and reproductive health.

YW

Children and young people and their families can access information and advice to help them make healthy choices

You're Welcome includes provision that parents and carers are provided with culturally sensitive information and support to discuss health issues with young people and that sexual health services provide young people with:

- Appropriate information and advice to help them develop their ability to make safe, informed choices
- Easy to understand information on a range of sexual health issues (such as STIs, sexuality and contraception).

M

Schools and health services work together to support children and young people's wellbeing

Young people say in the Manifesto that they want schools to play a greater role in health and wellbeing. This includes:

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

YW**M****P**

Children and young people's emotional and mental health needs are met

Young people say in the Manifesto that they want to see health professionals, service providers and commissioners taking mental health as seriously as physical health.

Health agencies have pledged to improve the mental health of children and young people by promoting resilience and mental wellbeing and providing early and effective evidence based treatment for those who need it.

You're Welcome includes provision that services ensure that the emotional, psychological and spiritual needs of young people are met and that a clear referral pathway is identified for young people with identified emotional and mental health concerns (which includes specialised CAMHS input where appropriate).

P

Prevention and tackling health inequalities is prioritised

Health agencies have pledged:

- That good mental and physical health and early interventions, including for children and young people with long term conditions, will be of equal importance to caring for those who become acutely unwell
- To reduce child deaths through evidence based public health measures
- To prevent ill health for children and young people and improve their opportunities for better long-term health by supporting families to look after their children, when they need it
- To support and protect the most vulnerable by focusing on the social determinants of health and providing better support to the groups that have the worst health outcomes.

Wellbeing & prevention Observations

The Manifesto's strong messages on the role of schools raises the challenge of how wider public services can be brought into the narrative on children's health rights. There is also the related challenge of maintaining a rights based narrative in the transition of public health services to local authority commissioning. The NHS Constitution is mainly applicable to services provided or commissioned by NHS bodies, rather than the broader roles of local authorities and schools, for example.

Mental health is a particularly live issue with the establishment of the CAMHS taskforce and development of the parity of esteem agenda, so new descriptors of children's rights in health should be drafted so as to reflect any improvements brought about by this. Another challenge is to continue to promote positive messages about supporting mental wellbeing, while continuing to hold the NHS to account for delivering an adequate service when treatment is required.

Further reading

Department of Health (2014) *Closing the gap: priorities for essential change in mental health*

www.gov.uk/government/publications/mental-health-priorities-for-change

NHS England (2014) *Our Ambition to Reduce Premature Mortality: A resource to support commissioners in setting a level of ambition*, Chapter 2 (Prevention and health promotion)

www.england.nhs.uk/ourwork/sop/red-prem-mort/php/

Department of Health (2013) *Public Health Supplement to the NHS Constitution*

www.gov.uk/government/publications/the-nhs-constitution-for-england

Public Health England – Adolescent health framework

This briefing has identified a range of shared messages, in 8 areas, across the key documents that inform the development improvement and day-to-day work of children and young people's health services.

Conclusion

Conclusion

The documents reviewed have different roles and statuses, as set out in the introduction, and it is important to reflect on what this reveals about how the policy framework supports our aspirations for child health services.

The Children and Young People's Manifesto for Health and Wellbeing contains messages on particular issues such as how collective involvement should be carried out as well as calling for preventative action, for example through schools, which is not fully reflected in the other documents. The better health outcomes for children and young people Pledge has more strategic focus, so while highlighting issues such as access to services, integration, prevention and involvement as areas for improvement, it does not make specific prescriptions about a child or young person's individual interactions with the health service.

While the NHS Constitution has a statutory footing, it is not always clear what the rights it sets out mean for children. Furthermore, while it is relatively comprehensive about a typical patients' engagement in individual decisions, confidentiality and complaints, it is less detailed about the aspects of integration that are important to children – such as in the transition to adults services – and is perhaps less well placed to set out a clear approach to preventative work carried out outside traditional health services.

You're Welcome is the most comprehensive of the documents we reviewed and includes details about young people-friendly health services that will be of clear relevance to commissioners, service managers and professionals alike. It does not, however, always properly translate the strength of ambition and rights based approach that has been taken forward through the NHS Constitution and other more recent developments in health policy. It also contains little detail about what young people should be able to expect in the handling of complaints. As a document that informs high quality services for young people it will be important that it is updated so as not to downplay young people's rights and properly reflects the approach that young people have said they want.

Appendices

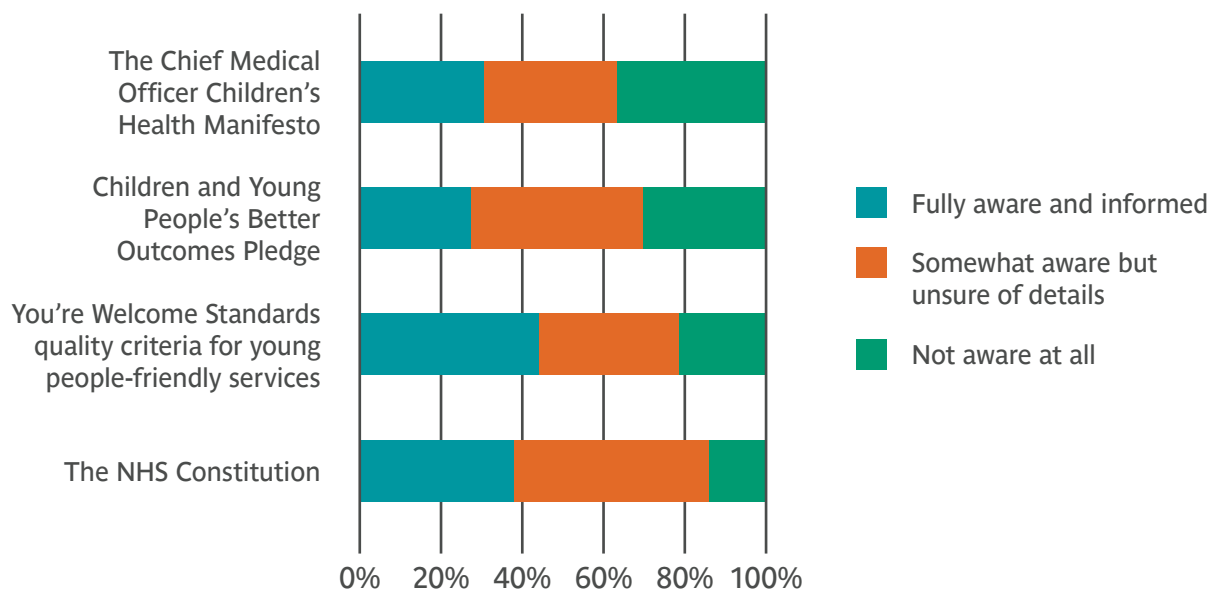
Appendix A

Key messages from front line professionals' survey

To find out how these different documents influence frontline health professionals' practice we carried out a simple survey. This survey asked professionals simple questions about the levels of awareness and influence associated with different documents and policy levers.

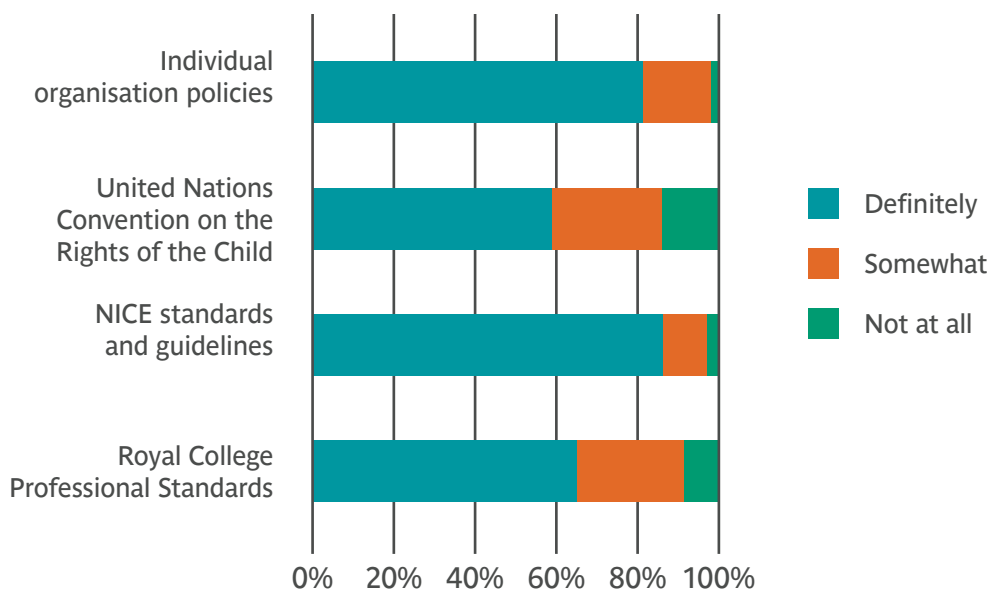
Results of survey

Which, if any, of the following documents that focus on the rights and expectations of children and young people when using health services are you aware of?



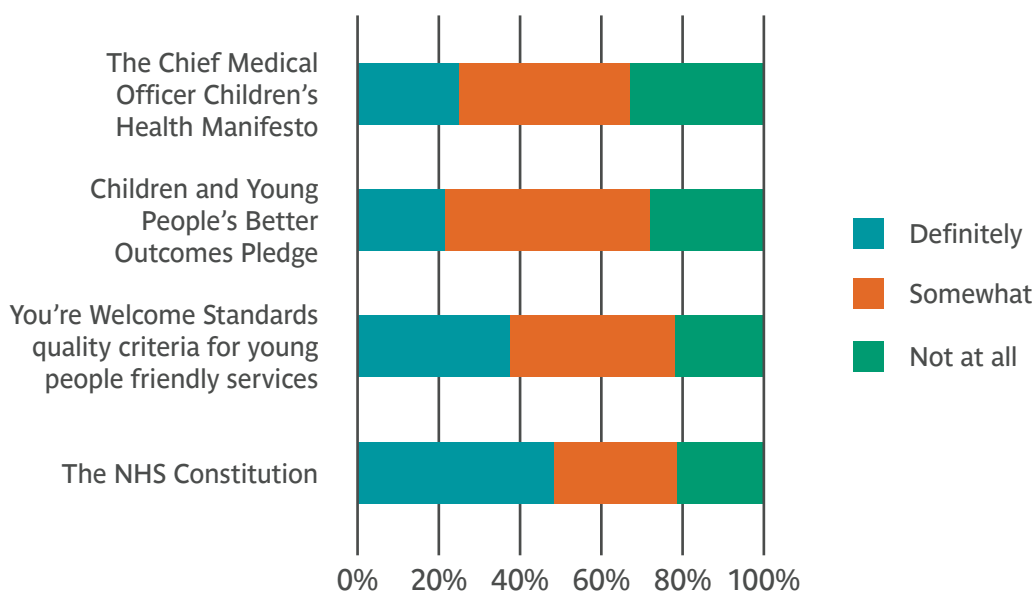
The NHS Constitution had the highest rate of recognition of the four documents, with over 85% being at least somewhat aware of it, although a majority of respondents were at least somewhat aware of all the documents.

Which, if any, of the following documents inform your organisation's approach to working with children and young people?



The survey also asked what additional documents or policies influenced professionals' practice, and interestingly respondents reported all of these documents as having a greater influence on their practice than the NHS Constitution, despite the differing status of these documents. Individual organisations' policy were the most significant influence on frontline professionals' practice and highlights the importance of working with individual organisations to embed key principles within their own policies and procedures.

Which, if any, of the following documents inform your organisation's approach to working with children and young people?



When asked about how these documents influenced their practice, all documents had some influence on the large majority of respondents but it was the NHS Constitution that had the highest degree of influence. This potentially reflects the statutory status of the NHS Constitution relative to the other non statutory documents.

Appendix B

Summary table

This table gives a quick summary of the combined messages and the coverage of each issue (in general) by the four documents reviewed.



NHS Constitution



You're Welcome quality criteria



Children and Young People's Manifesto for Health and Wellbeing



Better health outcomes for children and young people 'Pledge'

		C	YW	M	P
Availability and access	Decisions about Commissioning should be based on assessment of children and young people's needs				
	Children and young people are provided with information on how to access services				
	Children and young people have timely access to services				
	Service settings and their location provide for independent and non-stigmatising access for children and young people				
	There is provision to ensure the meeting of needs of children with complex needs or access challenges				
	Children and young people will not be turned away from services unreasonably				
Clinical quality	Staff have appropriate training in the care of children and young people				
	Treatment and settings are safe				
	Settings are designed with children and young people's comfort in mind				
	Pain is managed appropriately				
	Assessment and care planning considers the needs of the whole child				
Communication, confidentiality, respect	Professionals will communicate with children and young people in an appropriate way that values them and ensures they understand what is being communicated				
	All information should be provided in a way that can be clearly understood by children and young people to help them take part in decision making				
	Children and young people's privacy and confidentiality is taken seriously by professionals and services				
	Children and young people have control over information				
	Children and young people are treated with dignity and respect				

		C	YW	M	P
Complaints	Children and young people and their families have the information and support they need to make complaints are kept informed throughout the process				
	If a child or young person or their family makes a complaint they are treated with respect				
	There are mechanisms to complain or appeal to a third party				
	An appropriate response is received to the complaint				
Individual involvement in decisions	Children and young people are supported to take part in decisions about their own care and support				
	Children and young people will be able to give informed consent to their treatment				
	Children and young people will be provided with appropriate information to make informed decisions about treatment and consent				
	Child and young people are able make choices about the services commissioned by the NHS				
Collective involvement	Children and young people are involved in the routine planning of health services				
	Children and young people are consulted on any proposed changes to services				
	Children and young people are given the information and support they need to influence and scrutinise the planning and delivery of services				
	Children and young people are involved in evaluation of services				
	Children and young people are included in patient surveys				
	There are effective provider-level feedback mechanisms				
	Lessons from the views and experiences of children and young people collected in the past are shared, built on and acted on				
Integration and transition	Children and young people will experience integrated care				
	Services will work together to make the transition in and out of services, and between different services as smooth as possible.				
	Children and young people will be supported in making the transition from children's to adult services				
	Children and young people looked after by the local authority will receive specific support to manage the transition between services				
Wellbeing and prevention	Children and young people's contact with health services is used as an opportunity to promote wellbeing and healthy lifestyles				
	Children and young people and their families can access information and advice to help them make healthy choices				
	Schools and health services work together to support children and young people's wellbeing				
	Children and young people's emotional and mental health needs are met				
	Prevention and tackling health inequalities is prioritised				



This report is one of 2 reports published by CDC and NCB on the NHS Constitution

This report and the accompanying publication can be downloaded from
www.councilfordisabledchildren.org.uk/nhsconstitution

The National Children's Bureau is a leading research and development charity that for 50 years has been working to improve the lives of children and young people, reducing the impact of inequalities. We work with children, for children to influence government policy, be a strong voice for young people and front-line professionals, and provide practical solutions on a range of social issues.

For more information visit **www.ncb.org.uk**

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.

www.councilfordisabledchildren.org.uk

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