Engaging with local health partners
A toolkit for parent carer forums

Contents

Foreword .................................................................................................................................................. 2
Introduction ........................................................................................................................................... 3
Who are the decision-makers in health services? ............................................................................. 4
How are decisions about health services made? ............................................................................... 7
Using national legislation and policy to influence your local commissioning .................................. 8
Getting to know your local system ........................................................................................................ 13
Action planning .................................................................................................................................... 14
Summary and case study ......................................................................................................................... 15
Appendix 1 ............................................................................................................................................. 17
Appendix 2 ............................................................................................................................................. 21
Foreword

From the National Network of Parent Carer Forums

In partnership with Contact a Family and NHS England, the National Network of Parent Carer Forums (NNPCF) was delighted to be able to plan and co-host the largest ever national gathering of parent carer forums and local and national health partners in London on 14 March 2016.

This conference was timely: the Children and Families Act 2014 and the impending Ofsted/Care Quality Commission Inspections (May 2016) focussed attention on the collective responsibilities of local areas to improve life outcomes for children and young people with special educational needs and disabilities (SEND) and their families. This includes particular responsibilities for local health partners for whom increased co-production and participation with parent carers at a local, regional and national level is something we are keen to encourage.

Parent carer forums have a central role to play at a strategic level locally, and through the NNPCF regionally and nationally, on health policy and its implementation. The evidence supporting the value of co-production is well known; it is embedded in both Section 19 of the Children and Families Act and in the Special Educational Needs and Disability Code of Practice.

Contact a Family’s health project (2015/16, whose learning is summarised in this toolkit) will make a vital contribution to helping forums and the NNPCF to play these strategic roles. Working with forums in nine pilot areas across England, the project sought to build understanding and joint strategic working between parent carer forums and Clinical Commissioning Groups (CCGs) locally.

That learning was shared with delegates at our conference in March and, through this toolkit, it is now widely available to all parent carer forums in England. There is no doubt that closer relationships are needed between CCGs and forums to make real on the promises from the Children and Families Act for better life (and health) outcomes, for all children and young people with SEND, through their Education Health and Care Plans, via SEN Support, and for health needs covered by the statutory medical conditions guidance for schools.

We know that many forums and some regions (such as the East of England) are already underway and can evidence the value of co-production in improving health outcomes. We hope now that these resources can support even more strategic working, involving all forums, CCGs and other health commissioners. It is also something we, the NNPCF Steering Group, want to build on and develop through our continued close working with Contact a Family and our dialogue and joint working, at a national level, with NHS England, the Department of Health and others. We hope you will join us.

NNPCF Steering Group April 2016
Introduction to this toolkit

There is a recognised need to engage health commissioners and practitioners in implementing the SEND reforms. Their involvement is critical to ensuring that there is a range of health provision available locally which meets the needs of disabled children, young people and their families.

However, whilst there are emerging examples of good practice, in the most recent (the 6th Department for Education) SEND survey results, 56% of parent carer forums reported that there are significant gaps in health services, pathways and eligibility criteria information in their local offer.

We know that there are particular challenges for parent carer forums in engaging with health commissioning at a strategic level. Forums may have good relationships with service providers and with their local children’s commissioner, but then struggle to engage senior leaders in the Clinical Commissioning Group (CCG), or members of the Health and Wellbeing Board in developing support for disabled children, young people and their families.

This toolkit has therefore been developed specifically to support parent carer participation in health commissioning at this strategic level. We hope it will help forums to develop their understanding and confidence about:

- who makes decisions about health services locally and nationally
- the health commissioning process
- national legislation and policy that can support parent carer participation in health commissioning
- how to get to know your local system
- how to use local plans and priorities to influence local commissioning
- developing outline action plans for future activity.

The toolkit is based on the Working Together Workshop developed for the Contact a Family Health project by Anna Gill and Mel Theobald. To find out more about this workshop, and other support available to parent carer forums in working with health, contact your regional parent carer participation adviser.
Who are the decision-makers in health services?

There are lots of different organisations involved in making decisions about health services. It is an ever changing landscape and can feel incredibly complex – even for those working within health services – so don’t feel you need to develop an in-depth knowledge of the intricacies of health commissioning in order to get involved.

However, having some knowledge of who the key players are, how decisions are made, and who is accountable for what, will help you to focus your energies on the right people and feel more confident in engaging with health commissioning.

Below is a summary detailing what each of the health organisations you may hear about does.

**National leaders**

- **Department of Health** – led by the Secretary of State for Health, the Department of Health sets the overall budget for the NHS, the direction for the NHS (in a ‘Mandate’ published each year), and monitors NHS performance against these targets. The Secretary of State for Health is responsible to Parliament for the overall performance of the NHS.

- **NHS England** – responsible for commissioning some services directly, including GPs and other primary care services, and specialised services which are used by a comparatively small number of people, and therefore tend to be provided in a smaller number of specialist centres. NHS England is also responsible for funding and providing support and guidance to Clinical Commissioning Groups (see below) and for managing their performance. It also develops payment tariffs, standard contracts and quality guidelines used across the NHS and brings together experts from across the NHS to improve quality and develop best practice.

- **Public Health England** – provides national leadership for public health and provides support to local public health services. Areas that PHE is responsible for include prevention and early detection of health problems, infectious disease prevention, control and outbreak management; emergency preparedness and response and health intelligence and information.
Organisations which advise, support and regulate health

Healthwatch – there is a Healthwatch in every local authority area across England as well as a national body, Healthwatch England. Healthwatch works with people using health and social care services, with charities and local organisations, to form a picture of what matters to patients and carers and to help improve services.

Commissioning Support Units (CSUs) – can provide support for commissioners across a range of areas such as service redesign, procurement and contract management, information analysis and importantly communications and patient engagement. There are seven CSUs in England. These are:

- NHS South, Central and West CSU  ➤ www.sowcsu.nhs.uk
- NHS Midlands and Lancashire CSU  ➤ www.midlandsandlancashirecsu.nhs.uk
- NEL CSU (London and East of England) ➤ www.nelcsu.nhs.uk
- NHS North of England CSU ➤ www.necsu.nhs.uk
- NHS North West CSU ➤ www.northwestcsu.nhs.uk
- NHS South East CSU ➤ www.southeastcsu.nhs.uk
- NHS Yorkshire and Humberside CSU (this organisation has ceased to exist from March 31st 2016 further details have yet to be announced) ➤ http://yhcs.org.uk

Clinical Senates – bring together experts from across the NHS to provide advice on healthcare for a regional population on priority service areas.

Care Quality Commission (CQC) – the independent regulator of health and adult social care services in England. It inspects services to ensure they are providing people with safe, effective, compassionate, high-quality care and encourages services to improve. The CQC will have a pivotal role in the new SEND joint area inspections from May 2016.

Parliamentary and Health Service Ombudsman – accepts complaints at an individual rather than collective level, if a member of the public believes there has been injustice or hardship because an organisation has not acted properly or fairly, or has given them a poor service and not put things right.

NHS Improvement – a new organisation formed by a merger between Monitor and the Trust Development Authority (TDA). It is responsible for regulating NHS Trusts and Foundation Trusts to make sure they are run effectively. Information from CQC inspections is part of their assessment but they also look at other information about trusts’ finances and leadership.

Health Education England – exists for one reason only: to support the delivery of excellent healthcare and health improvement to the patients and public of England by ensuring that the workforce has the right numbers, skills, values and behaviours, at the right time and in the right place.
**Local planners**

- **Clinical Commissioning Groups (CCGs)** – most of the NHS commissioning budget is now managed by 209 clinical commissioning groups (CCGs). These are groups of general practices which come together in each area to commission the best services for their patients and population. CCGs are responsible for commissioning a wide range of services from urgent and emergency care, to planned care in hospitals and health services based in the community, including children’s healthcare services, mental health services, speech and language therapy and wheelchair services.

- **Local authorities** – responsible for commissioning public health services for their local population. This includes children’s public health (0–19), mental health promotion, physical activity and obesity programmes, and the NHS Health Check Programme. They are also responsible for convening the Health and Wellbeing Board and funding local Healthwatch (see below).

- **Health and Wellbeing Boards** – bring together the NHS, public health, adult social care and children’s services including elected representatives (local Councillors), Local Healthwatch. It is responsible for undertaking the Joint Strategic Needs Assessment, which maps out the health profile and needs of the local population, and the Joint Health and Wellbeing Strategy that sets out the priority and strategy for meeting those needs.

That’s quite a list! But this diagram, developed by the Council for Disabled Children, may help you to put it into context. The inner circle shows the range of services that a particular child or young person and their family might use. The next circle shows who is responsible for commissioning these services, while the outer circle shows the Health and Wellbeing Board which has strategic responsibility for making sure that the right services are available locally for all families.
Further resources

The King’s Fund
Has also produced an *Alternative guide to the NHS* animation which is a great introduction to the health commissioning landscape and how it all fits together at:


Council for Disabled Children
Has also developed detailed resources as part of its Expert Parent Programme and an e-learning session for parents called a *Guide to the workings of the NHS*, which you may find useful.

How are decisions about health services made?

The commissioning process

*Commissioning* is a strategic and proactive process of identifying the healthcare needs of a given population and prioritising services to meet local needs within the resources available. It entails securing the service provider(s) and specifying monitoring systems that will maximise health and wellbeing, minimise illness and reduce inequalities.

The diagram below shows the NHS commissioning cycle. It describes the process that anyone commissioning health services nationally or locally should follow: from understanding what services are needed, to designing and procuring them, to managing performance and gathering evaluation data to inform future planning. As the blue circle indicates, patients and the public should be at the heart of the process, with their voices heard at every stage.
The role of a commissioner is to make the best use of all available resources to maximise the health and wellbeing of the local population. However, it’s important to recognise that the resources they have available are finite and so there will always be a process of prioritisation in deciding what services will get commissioned.

By engaging with health commissioning, parent carer forums have an important role to play in making sure that disabled children and their families don’t miss out when priorities are being set.

**Using national legislation and policy to influence your local commissioning**

There are a range of national levers that you can use to help you make the case for being included in the commissioning process and for ensuring that there is a focus on the needs of children, young people and families.

**NHS Constitution**

The NHS Constitution establishes the principles and values of the NHS in England, starting with the statement ‘the NHS belongs to the people’.

It outlines the rights that you have in relation to involvement in your healthcare and the NHS:

- You have the right to be involved in planning and making decisions about your health and care with your care provider or providers, including your end of life care, and to be given information and support to enable you to do this. Where appropriate this right includes your family and carers. This includes being given the chance to manage your own care and treatment, if appropriate.
- You have the right to an open and transparent relationship with the organisation providing your care. You must be told about any safety incident relating to your care which, in the opinion of a healthcare professional, has caused, or could still cause, significant harm or death. You must be given the facts, an apology and any reasonable support you need.
- You have the right to be involved, directly or through representatives, in the planning of healthcare services commissioned by NHS bodies, 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.
It also outlines a number of pledges by the NHS to enable people to realise these rights. The NHS pledges to:

- provide you with the information and support you need to influence and scrutinise the planning and delivery of NHS services
- work in partnership with you, your family, carers and representatives
- involve you in discussions about planning your care and to offer you a written record of what is agreed, if you want one
- encourage and welcome feedback on your health and care experiences and use this to improve services.

**Health and Social Care Act 2012**

The Health and Social Care Act 2012 introduced significant amendments to the NHS Act 2006, especially with regard to how NHS commissioners will function. It defines a number of legal duties which are important for parent carer participation in health commissioning.

**Duty to promote involvement of each patient**

NHS England and Clinical Commissioning Groups (CCGs) must:

> “promote the involvement of patients and carers in decisions which relate to the prevention or diagnosis of illness in the patients, or their care or treatment.”

**Duty as to patient choice**

NHS England and CCGs must:

> “act with a view to enabling patients to make choices with respect to aspects of health services provided to them.”

**Public participation duties on CCGs and NHS England**

The Act places a requirement on CCGs and NHS England to ensure public involvement and consultation in commissioning processes and decisions. A description of these arrangements must be included in a CCG’s Constitution and both NHS England and the CCG must report on how they have met their public participation duties in their annual reports.

A **Patient and Public Participation Policy** was published by NHS England in November 2015, this includes the NHS’s Ladder of Engagement and Participation. The ladder outlines a variety of forms of engagement and participation. The policy states it is to be used as a best practice tool by NHS England staff in a flexible way to ensure appropriate and proportional participation.

Although the NHS version uses slightly different wording, it has the same basis as the ladder commonly used within the world of parent carer participation (as shown below).
The purpose of this toolkit is to give forums the tools and confidence to engage with health commissioners in their own language and ways of working. It is therefore worth noting that whilst we all use the words informing and consulting, the NHS uses ‘involving’ and ‘collaborating’ where in forums we prefer to use the terms ‘participation’ and ‘co-production’. We are all talking about the same principles but need to reach a shared understanding – a good start for any partnership working.

The ladder of participation as used within parent carer participation
Duty to reduce health inequalities

NHS England and Clinical Commissioning Groups (CCGs) must:

“have regard to the need to reduce inequalities between patients with respect to their ability to access health services … and [to] the outcomes achieved for them by the provision of health services.”

NHS England has produced Transforming participation in health and care guidance to help commissioners to understand these statutory responsibilities and support them to improve individual and public participation.

The Health and Social Care Act 2012 also amends the Local Government and Public Involvement in Health Act 2007 to introduce duties and powers for Health and Wellbeing Boards in relation to Joint Strategic Needs Assessments and Joint Health and Wellbeing Strategies.

**Department of Health statutory guidance** explaining these duties states that:

“Health and Wellbeing Boards must involve the local Healthwatch organisation and the local community, and this should be continuous throughout the Joint Strategic Needs Analysis (JSNA) and Joint Health and Wellbeing (JHWS) process.”

The guidance also emphasises that involvement should be inclusive and engage socially excluded and vulnerable groups, and people with particular communication needs.

**The Children and Families Act 2014**

The Children and Families Act 2014 places new duties on health commissioners (CCGs and NHS England) in relation to identifying and meeting the needs of disabled children and young people with special educational needs, including duties to work with the local authority to jointly commission services.

Section 19 of the Act also creates new duties to involve children, young people and their families, having regard to:

- the views, wishes and feelings of the child, young person or parent
- the importance of their full participation in decisions
- the importance of their being provided with the necessary information and support to participate
- the need to support the child or young person to achieve the best possible educational and other outcomes, preparing them effectively for adulthood.

**Chapter 1 of the SEND Code of Practice** clearly outlines duties on local authorities and their health partners regarding involving children, young people and parents in planning, commissioning and reviewing services and not just at an individual support level. Indeed, para 1.13 of the Code specifically refers to parent carer forums – something that forums might like to draw to the attention of their local CCGs.
The Council for Disabled Children has produced a very detailed self-audit tool for CCGs to meet their new duties under the Act, this has been trialled with several CCGs already, but most areas will not yet be aware of this tool – so it might be a useful introduction to a more strategic, co-production-based relationship. The tool can be downloaded at:

http://councilfordisabledchildren.org.uk/media/1106619/ccg-audit-tool-final.xlsx

This toolkit also references the Disability Matters resources that the NNPCF has been involved in developing.

Considering the 0–25 age remit of parent carer forums, it is also worth bearing in mind that the need for culture change to focus on wellbeing and ‘voice’ is also a core component of the Care Act 2014.

Other national policy levers which may be useful in influencing health provision for children, young people and families include:

You’re welcome – quality criteria for young people friendly health services, published in 2011

Children and young people’s manifesto for health and wellbeing – published in the Chief Medical Officer’s Annual Report 2012

Better health outcomes for children and young people – a pledge from national system-leading organisations, published in 2013

We would like to make a change – report on children and young people’s participation in strategic health decision-making – published by the Office of the Children’s Commissioner in 2013

Facing the future: Together for child health – a new set of standards for acute care, developed jointly by the Royal College of Paediatrics and Child Health, the Royal College of General Practitioners and the Royal College of Nursing, published in 2015

Future in mind – the report of the work of the Children and Young People’s Mental Health Taskforce on promoting, protecting and improving our children and young people’s mental health and wellbeing – published in 2015.
Getting to know your local system

Having knowledge of the national framework in which local decision-makers are working is useful but local areas also have a significant degree of freedom to set priorities, and commission services according to the needs of their particular population.

So when engaging with local health commissioners, it is useful to do some preparation by finding out what priorities have been set locally and who your key contacts are. If there has previously been a forum in the area then it might be useful to link with parent carers who were involved and see if they will work with you.

At the end of this toolkit you will find a template which your forum can use to help you map out your local health system and identify:

- the people and organisations involved in health commissioning in your area
- what the priorities and plans for health commissioning are locally.

Using local priorities and plans to influence commissioning

When looking at local plans, if you find that support for disabled children and young people and their families has already been identified as a priority it gives your forum a great ‘in’ to start a conversation with your local health commissioners, about how you can work with them to make it happen.

However, it’s important to be aware that local health commissioners may have different priorities to your own. Being a health commissioner means trying to balance the needs of many different groups and populations, and trying to get the best value from the resources you have available. The King’s Fund report, *Transforming our healthcare system: 10 priorities for commissioners* describes just some of the many other things that may be a priority for health commissioners in your area.

If support for disabled children and young people and their families hasn’t been identified as a priority within your area, don’t forget that you may still be able to use existing priorities as a lever to improve health services.

For example, perhaps your forum is concerned that the Children’s and Adolescent Mental Health Service (CAMHS) in your area is not able to meet the needs of disabled children who also have mental health problems. This may not be specifically identified as a priority in your local plans, but “improving the management of patients with both mental and physical health needs” has been. This might be an opportunity to contact commissioners to explain how many disabled children also experience mental health problems and that currently CAMHS is not able to properly support them because they have other needs in addition to their mental health. So, they are exactly the type of patient that commissioners have prioritised improving the management of.
Action planning

Hopefully having read the previous sections of this toolkit you’ve started to get a better understanding of how health commissioning works and some of the national and local levers you can use to help your forum get involved. The next step is to put this into action.

Here are some top tips to help you get started:

- **Spend time identifying your priorities** – it is easy to get overwhelmed by the scale of the challenge, so spend some time identifying your priorities and focus your efforts into taking one or two of these forward.

- **Agree SMART outcomes to work towards** – these describe the Specific, Measurable, Achievable, Realistic and Time-bound changes you want to achieve, and by when. These changes should be ones that are also realistic and reasonable, taking into account the capacity and resources that you have as a forum.

- **Consider ‘quick wins’ as well as big service changes** – starting small and tackling something that may be quite easy to change gives you the opportunity to build the relationships with commissioners that will help you to make bigger changes later on.

- **BUT: think strategically** – and don’t get involved in individual issues – make sure you’re focusing on achieving change that will benefit lots of families in your area.

- **Build your case and collect evidence for your position** – once you’ve decided what you want to change build your case and collect evidence for your position. The evidence you use is likely to include feedback and case study examples from local parent carers. You could also look at other data that is available for your local area, for example, local health profiles provide a snapshot overview of health for every local authority area in England and there are also separate profiles for child health and wellbeing. It’s worth also having a look at what’s happening in other areas and whether there are examples of good practice that your local authority could learn from. Your Contact a Family regional parent carer participation advisor may be able to help you with this.

- **Be clear about your key messages and keep repeating them** – as one American political consultants says, “about the time that you’re absolutely sick of saying it is about the time that your target audience has heard it for the first time”.

- **Don’t feel that you have to do everything yourselves** – use partners and existing participation pathways such as Healthwatch to get your message across, and remember that you can use funding to bring in extra support for specific pieces of work.
Summary and case study

While getting involved in health commissioning may feel daunting at first, it’s important to remember that there was probably a time when you felt the same about working with your local authority to implement the SEND reforms.

Once you’ve spent some time developing your understanding and confidence in engaging with health, there’s so much your forum can achieve. Here is just one example of the impact that a parent carer forum had when working with their local health partners.

**North East Lincolnshire Parent Participation Forum (NELPPF)**

We are funded by the Department for Education and have been working in co-production with key partners across North East Lincolnshire since 2008. The families we represent are drawn from across North East Lincolnshire with many families from lower economic backgrounds and areas of deprivation. We are aware of and monitor the child health profile of NE Lincs as evidenced in the CHIMAT data and believe we have a wide, diverse and representative membership to draw on, thereby providing the CCG and partner delivery organisations both quantitative and qualitative views and input from parents.

We have used the CCG’s own engagement strategy and the newly published *NHS England patient and public participation policy* which contains the NHS ladder of engagement and participation (see page 10). The ladder of engagement outlines a variety of forms of engagement and participation. The policy states it is to be used as a best practice tool by NHS England staff in a flexible way to ensure appropriate and proportional participation. Using the different stages shown on the ladder, here are a few examples from the work that the North East Lincolnshire Parent Participation Forum has been engaged in.

- **Collaborating on a Care Act Event with Professor Luke Clements** – the forum co-produced this event with the CCG and Transitions Team in June 2015.

- **Outcome** – this event saw some great engagement working, all together, raising awareness to both families and professionals of their new rights as carers. This has also resulted in the forum being invited to sit down with children’s services to look at creating the local protocol for parent carer assessments.

- **Involvement in development of new building** – the forum were fundamentally involved in the development and planning for the new Assisted Living Building that has been recently launched; advocating for adequate changing facilities, hoists etc for disabled people as there is no provision within the main hospital building.

- **Outcome** – members of the public can come to the new purpose-built facility to find out what types of equipment are available, and what they are eligible for. It will enable children, young people and disabled adults to both gain independence and keep being more independent. See [www.nlgnhs.uk/services/assisted-living-centre](http://www.nlgnhs.uk/services/assisted-living-centre)
Feeding into consultation on new autism pathway – forum members and young people have been involved in a public consultation over a six month period on the children's autism provision. The feedback is helping provide the vital ‘evidence and build’ phase of the autism pathway/strategy that NELPPF are writing alongside health partners.

Outcome – expected outcome: the final pathway will have a higher credibility amongst families and be much more likely to meet locally identified need. Three simple questions were asked: • What Works? • What isn’t working? • What needs to be improved? The responses were gathered at events, workshops, schools, coffee mornings, online surveys, post-16 and Early Years settings, amongst others.

Informing – the NE Lincs SEN newsletter is a prime example of local collaboration and information sharing. The forum were the driving force in establishing this and now coproduce it with SENDIASS, NE Lincs Council, CCG and SERCO. This is a newsletter that provides information, guidance and advice to families and young people with SEN and goes out to over 3000 people via schools, children’s centres, hospitals, nurseries and post 16, clubs etc.

Outcome – more parents and carers are informed and supported to be involved in, and make decisions about their child’s education, health and care across all aspects of their lives. This is a core aim of the Children and Families Act 2014.

Suggestions for forums wanting to engage with health partners

We would suggest an initial informal, small, targeted meeting with CCG lead officers to scope out the following issues:

• identify the key successes/issues/challenges regarding the new duties on health partners in the SEND reforms
• how the forum could support the CCG to meet their obligations around parent engagement of children and young people with SEN and disabilities and therefore be OFSTED/CQC ‘ready’
• to agree priority areas for strategic engagement with the CCG as outlined in the table on page 18
• to agree structures, named leads and time lines to take this work forward.

The above information was taken from the NELPPF report after their involvement in the pilot project- Contact a Family and NHS England’s Parent Participation Project: a briefing for health colleagues March 2016

For further inspiration, you can find more case studies like this in the Sharing good practice: parent participation in health settings guide. This guide, and lots of other resources to support parent carer forum participation in health settings, is available on the Contact a Family website at:

www.cafamily.org.uk/parent-carer-participation/improving-health-services
Appendix 1

Local data collection template

The template below is a tool that parent carer forums can use to map out:

- the people and organisations involved in health commissioning in your area
- what the priorities and plans for health commissioning are locally

It may feel daunting to try to find this information initially, but it’s worth it, as having some understanding of who’s who and the local levers for influencing will make you feel much more confident when having conversations with commissioners.

If you’d like support with completing this template, please get in touch with your Contact a Family regional parent carer participation advisor.

Of course, every local area is slightly different, so you may find that some of the key contact roles mentioned don’t exist for your area. But if you’re able to identify one or two people in an organisation to contact initially, they should be able to signpost you to other relevant colleagues if necessary. The organisations you will be looking for information about are:

► **Your local Clinical Commissioning Group(s)** – with 209 CCGs and 152 local authorities in England, and different geographical boundaries for each, there is likely to be more than one CCG in your local authority area. CCGs are responsible for commissioning most health services locally. To meet their new duties under the Children and Families Act 2014 CCGs should have a place in a Designated Medical Officer (DMO) or a Designated Clinical Officer (DCO). This role and the associated responsibilities vary from area to area and there is no national mandate to dictate this. However, the Council for Disabled Children, in its role as the DfE’s strategic partner, produced a *Handbook for DMOs* which helps to clarify the SEND duties to be covered, and how the role is being developed across England.

► **Your local authority** – you will already have strong links with the local authority commissioners most directly involved in the SEND reforms, but it’s also important to be aware of the wider responsibilities that local authorities have for health and wellbeing, and to build relationships with those key contacts. Local authorities are also responsible for convening the Health and Wellbeing Board, which has overall strategic responsibility for planning healthcare services to meet local needs.

► **Local providers of health services** – while not responsible for commissioning decisions, it’s useful to be aware of which organisations are providing health services locally. There might be some things that providers can improve without involving commissioners, but they can also be allies when you are making the case to commissioners for greater priority to be placed on the needs of children and young people.

► **Your local Healthwatch** – local Healthwatch can work with parent carer forums to highlight gaps in health services for disabled children and young people. They might also be a useful source of information about who’s who locally.
Name of forum:

Date template completed:

**Clinical Commissioning Groups (CCGs)**

Our local CCGs are: [enter the names of your local CCGs]

To see which CCGs are responsible for commissioning in your area, you can find a map showing the geographical boundaries of all the CCGs in England at:

🔗 www.england.nhs.uk/resources/ccg-maps

**Mapping your local CCGs**

Copy and paste the table below, so you have one table per CCG, then complete the information. We have created a Word version you can download to use.

Once you have identified the CCGs within your local authority area, you can find their website links at:

🔗 www.england.nhs.uk/ccg-details

<table>
<thead>
<tr>
<th>Name of CCG</th>
<th></th>
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<tbody>
<tr>
<td>Website</td>
<td></td>
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<tr>
<td>Link(s) to CCG strategic and operational plans, any other useful documents, such as their engagement or participation strategy, and the CCG budget</td>
<td></td>
</tr>
<tr>
<td>What the CCG is responsible for commissioning</td>
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<tr>
<td>Stated strategic priorities for children and young people</td>
<td></td>
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<tr>
<td>Other strategic priorities identified</td>
<td></td>
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<tr>
<td>Gaps in plans/priorities relating to CYP with SEND</td>
<td></td>
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<tr>
<td>Names and details of key contacts, for example:</td>
<td></td>
</tr>
<tr>
<td>• CCG Accountable Officer (the Chief Executive of the CCG – may also be called the Chief Officer)</td>
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<tr>
<td>• CCG Children’s Lead</td>
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<tr>
<td>• Designated Medical Officer or Designated Clinical Officer (should be appointed by all CCGs to support them in meeting their statutory responsibilities for CYP with SEND)</td>
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<tr>
<td>• Children’s Commissioner</td>
<td></td>
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<tr>
<td>• CCG Lay Member (PPI) (all CCGs must have a lay member of their governing body who is responsible for ensuring that public and patients’ views are heard)</td>
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</tr>
<tr>
<td>• Participation Lead (within your CCG there is likely to be a paid member of staff with responsibility for engagement/participation)</td>
<td></td>
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</tbody>
</table>
**Mapping your local authority**

Key documents and contact details for your local authority relating to health and wellbeing should be available on its website. There’s a useful database of all local authority websites at:

🔗 http://local.direct.gov.uk/LDGRedirect/Start.do?mode=1

If you struggle to find the information online, you could ask one of your existing contacts within the council, or call the main switchboard number.

The King’s Fund also has a useful interactive map to help you find links to your local Health and Wellbeing Board, as well as to other relevant documents like the Joint Strategic Needs Assessment:

🔗 www.kingsfund.org.uk/projects/health-and-wellbeing-boards/hwb-map

We have created a Word version you can download to use.

<table>
<thead>
<tr>
<th>Name of local authority</th>
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<tbody>
<tr>
<td>Local authority website</td>
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<tr>
<td>What the local authority is responsible for commissioning</td>
<td></td>
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<tr>
<td>Link to Health and Wellbeing Board web pages</td>
<td></td>
</tr>
<tr>
<td>Links to Joint Strategic Needs Assessment and Health and Wellbeing Strategy</td>
<td></td>
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<tr>
<td>Stated strategic priorities for children and young people</td>
<td></td>
</tr>
<tr>
<td>Other strategic priorities identified</td>
<td></td>
</tr>
<tr>
<td>Gaps in plans/priorities relating to children and young people with SEND</td>
<td></td>
</tr>
<tr>
<td>Names and details of key contacts, for example:</td>
<td></td>
</tr>
<tr>
<td>• Chair of Health and Wellbeing Board</td>
<td></td>
</tr>
<tr>
<td>• Executive member for health (a councillor who is part of the local cabinet and has responsibility for health. In most areas this will be the same as the Chair of the Health and Wellbeing Board)</td>
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<tr>
<td>• Director of Public Health</td>
<td></td>
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<tr>
<td>• Joint Commissioning Lead</td>
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</tbody>
</table>
Mapping your local statutory health providers

You can find full listings of all the Trusts and Authorities providing health services in England at:

- [www.nhs.uk/servicedirectories/pages/nhstrustlisting.aspx](http://www.nhs.uk/servicedirectories/pages/nhstrustlisting.aspx)

If you’re not sure which trusts you’re looking for, it may be easier for you to use the NHS Choices ‘Find services’ page, where you can search by type of service and postcode or town:

- [www.nhs.uk/service-search](http://www.nhs.uk/service-search)

The types of providers it might be useful to find out about are: local hospitals in your area, community health services (including mental health services), and child development centres.

The types of contacts you may be looking for – if they’re available – include Patient Advice and Liaison Services (PALS) in your local hospitals, lead clinicians and nurses for children and young people, centre coordinators and managers, and participation/engagement leads. Or, if in doubt – start at the top – a letter to the Chief Executive can be an effective way to raise an issue and be put in touch with the person responsible.

<table>
<thead>
<tr>
<th>Name of provider</th>
<th>Area covered and services available</th>
<th>Lead contact(s)</th>
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</table>

Identifying your local Healthwatch

You can search for your nearest Healthwatch, find links to their website, and email addresses at:

- [www.healthwatch.co.uk/find-local-healthwatch](http://www.healthwatch.co.uk/find-local-healthwatch)

<table>
<thead>
<tr>
<th>Lead Contact</th>
<th>Contact details</th>
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We have created a Word version you can download to list your statutory health providers and Healthwatch.
Appendix 2

Top tips for clearer and more transparent Clinical Commissioning Group (CCG) websites

This appendix gives guidance for you to share with CCGs looking to make their websites clear and accessible to families, parent carers, and wider members of the public.

Rules of thumb

People visit a website for one key reason – to find out information: so a CCG website needs to ensure there is basic and unambiguous information about who does what, what their role is, what the role is actually called, and what they are responsible for.

Other good practice:

• there needs to be a clear line of accountability and the management structure within the CCG
• ensure contact details are easily accessible and include phone numbers and email addresses
• the reader needs to be able to clearly see your vision, your aims, and most importantly what the Board and CCG staff are doing about it – as in what you are going to deliver, for whom, by whom and by when
• a good transparent strategy will clearly define what the outcomes will be if it is put in place – that means, what difference it will make/what difference will people be able to see.

To achieve this CCGs can:

• develop a simple format, make the structure of the site logical and consistent and include a site map for ease of navigation
• have a clear front page that is easy to use and contains simple concise information with links
• use menus and links to ensure the website is easy to navigate
• ensure there are not too many navigation buttons while leading into more sections, it may just leave a user with too many choices; less is more
• use obvious section names. Obscure, general words like ‘resources’ and ‘tools’ should be avoided when possible, as they only lead to users clicking on multiple buttons before finding what they are looking for
• have a clear search function
• think about the use of colours and don’t over complicate. Also remember that blue text can be confused with hyperlinks so choose shades of blue carefully
• think about text and font size, avoid underlining as it is easy to confuse this with a hyperlink
• don’t use jargon and ensure there is a list of abbreviations if needed
• think about accessibility for disabled users
• where an area has more than one CCG look at neighbouring CCG websites to understand how they present information. Is it possible to use a similar format, and to link across to demonstrate any partnership working?
If a CCG is working with other CCGs in the area, the website needs to reflect this and link from one area to another — always be mindful that in general, the public don’t know or care what CCG they come under, they just want to know about the plans for families and carers across their local area.

Example of an easy to navigate clear website – North East Lincolnshire CCG

www.northeastlincolnshireccg.nhs.uk

For further information:

Plain English Campaign: Tips for clear websites

www.plainenglish.co.uk/files/websitesguide.pdf