

Quick Guide:

Guidance for health services for children and young people with Special Educational Needs and Disability (SEND)



NHS England Information Reader Box

Directorate

Nursing

Publications Gateway Reference: 06209

Document purpose	Guidance
Document name	Quick Guide Health services for children and young people with Special Educational Needs and Disability
Author	NHS England
Publication date	12 July 2018
Target audience	CCG Clinical Leaders, CCG Accountable Officers, CSU Managing Directors, Care Trust CEs, Foundation Trust CEs , Medical Directors, Directors of PH, Directors of Nursing, Local Authority CEs, Directors of Adult SSs, NHS Trust Board Chairs, NHS England Regional Directors, NHS England Directors of Commissioning Operations, Allied Health Professionals, GPs, Communications Leads, Directors of Children's Services, NHS Trust CEs
Additional circulation list	N/A
Description	This Quick Guide aims to give health commissioners and providers of services a quick resource to support services for children and young people with Special Educational Needs and Disability (SEND), introduced by Part 3 of the Children and Families Act 2014.
Cross reference	Quick Guide: Commissioning for transition to adult services for young people with Special Educational Needs and Disability (SEND)
Superseded docs (if applicable)	N/A
Action required	N/A
Timing / deadlines (if applicable)	N/A
Contact details for further information	Nursing & Midwifery Skipton House 80 London Road London SE1 6LH ENGLAND.CCNSENDBoard@nhs.net

Document Status

This is a controlled document. Whilst this document may be printed, the electronic version posted on the intranet is the controlled copy. Any printed copies of this document are not controlled. As a controlled document, this document should not be saved onto local or network drives but should always be accessed from the intranet.

Quick Guide

Health services for children and young people with Special Educational Needs and Disability (SEND)

Version number: 7

First published: 12 July 2018

Prepared by: The Children with Complex Needs/Special Educational Needs and Disability (CCN SEND) Board.

Classification: OFFICIAL

Equality and Health Inequalities statement

Promoting equality and addressing health inequalities are at the heart of NHS England's values. Throughout the development of the policies and processes cited in this document, we have:

- considered the need to eliminate discrimination, harassment and victimisation, to advance equality of opportunity, and to foster good relations between people who share a relevant protected characteristic (as cited under the Equality Act 2010) and those who do not share it; and
- considered the need to reduce inequalities between patients in access to, and outcomes from, healthcare services, and to ensure that services are provided in an integrated way where this might reduce health inequalities.

See NHS England's [Equality and health inequalities legal duties guidance](#) for more information.

Contents

1	Introduction	6
1.1	Working with schools and colleges	7
2	Statutory framework	7
2.1	Joint commissioning	8
2.2	Local leadership and partnership working	8
3	Clinical Commissioning Group role	9
4	Designated Medical Officer or Clinical Officer role	12
4.1	Overview of the role	12
4.2	Local considerations re strategic and operational functions	12
4.3	Additional support for designated officer roles	13
5	Education, Health and Care plan	13
6	Health contribution	14
6.1	Early identification	14
6.2	The beginning of the EHC plan process	15
6.2.1	Requesting advice if known to services	16
6.2.2	Requesting advice if not known to services	16
6.3	Monitoring of the timescale and health role	17
6.3.1	Timescales and exceptions	17
6.4	Working with other professionals around the child and family	17
6.4.1	Mental health	17
6.4.2	Health visiting and nursing	17
7	Engaging with families	19
7.1	Supporting and involving children and young people	19
7.2	Opportunities to involve parents/carers	19
7.3	Examples of working in partnership with parents	20
7.4	Information, Advice and Support Services	20
7.5	Complaints	20
7.6	Mediation and first tier tribunal trial	20

8	Data sharing	21
8.1	Patient Communication and Engagement	21
8.2	Processes and Governance	22
8.3	Security	22
9	Children’s and young people’s health data set	23
10	Patient Choice	24
11	Annex A: Process for requests where the child is not known to clinicians	26

1 Introduction

This Quick Guide aims to help health commissioners and providers tackle the challenges involved in implementing the joint commissioning of services for children and young people with Special Educational Needs and Disability (SEND) introduced by **Part 3 of the Children and Families Act 2014**.

It works in conjunction with the following existing national guidance:

- **Department of Health (DH) 2016 SEND resources for Healthcare Professionals Guide**
- **SEND code of practice: 0 to 25 years**

The Guide should be read in parallel with the NHS England Quick Guide commissioning transition to adult services for young people with Special Educational Needs and Disability (SEND) and the **Children and young people: Quick guide about personal health budgets and Integrated Personal Commissioning**.

14% of school children have an identified special educational need. A child or young person has SEND if they have a learning difficulty or disability which calls for special educational provision. A child of compulsory school age, or a young person, has a learning difficulty or disability if they:

- have a significantly greater difficulty in learning than the majority of others of the same age, or
- have a disability which prevents or hinders them from making use of facilities of a kind generally provided for others of the same age in mainstream schools or mainstream post-16 provision.

A child under compulsory school age has a learning difficulty or disability if they are likely to be within the above categories (or would be likely to be if no special educational needs provision was made).

Special educational needs can result from:

- a long-term condition or life-limiting condition, such as Duchenne muscular dystrophy
- a congenital condition, such as cerebral palsy
- a learning disability
- autistic spectrum disorder, including both autism and Asperger syndrome
- serious illness or injury, such as acquired brain injury
- a sensory impairment
- behavioural issues.

Many children and young people who have Special Education Needs (SEN) may have a disability. Disability is described under the Equality Act 2010 as a physical or mental impairment which has a substantial and long-term adverse effect on a person's ability to carry out normal day-to-day activities¹.

Local Clinical Commissioning Groups (CCGs) will be involved in the joint arrangements for the provision of care, enabling providers to access information via their commissioner, or via the Local Authority (LA). The LA will in some cases be the lead commissioner for children's services.

Some information will also be published in the **Local Offer** section of the LA website, which should reflect the health services available to a child or young person with SEND in accordance with the **Children and Families Act 2014 (Part 3 Information and Advice Section 30)**.

1.1 Working with schools and colleges

It is important that the health system works closely with the education system. All maintained nursery schools, mainstream schools, free schools and academies must have a Special Educational Needs Co-ordinator (SENCo). This postholder will be a key point of liaison for health professionals.

A child or young person's educational attainment can be affected by school absences due to hospitalisation, frequent appointments or lack of support to promote attendance. Schools and colleges can make their own valuable contribution by co-commissioning appropriate health and social care, to ensure that seamless support is available to these individuals.

2 Statutory framework

The **Children and Families Act 2014** introduced a number of new duties for CCGs to:

- commission services jointly for children and young people (up to age 25) with SEND, including those with Education Health and Care EHC plans
- work with the LA's to contribute to the Local Offer of services available
- ensure that health providers inform parents and the appropriate LA where they think that a young child under compulsory school age has, or probably has, SEN and/or a disability
- have mechanisms in place to ensure practitioners and clinicians will support the integrated EHC needs assessment process
- agree personal budgets, where they are provided for those with EHC plans.

1 **Equality Act 2010, Part 2, Chapter 1, Section 6**

2.1 Joint commissioning

Arrangements must be in place for considering and agreeing:

- what education, health and care provision is to be secured
- by whom education, health and care provision is to be secured
- what advice and information is to be provided about education, health and care provision
- by whom, to whom and how such advice and information is to be provided
- how complaints about education, health and care provision may be made and are to be dealt with
- procedures for ensuring that disputes between the parties to the joint commissioning arrangements are resolved as quickly as possible.

Joint commissioning arrangements for securing education, health and care provision must in particular include arrangements for:

- securing EHC needs assessments
- securing the provision specified in EHC plans
- agreeing personal budgets.

Every child or young person with a special educational need should benefit from the joint arrangements. The majority of children with special educational needs will not have an EHC plan but will have been identified as needing SEN support. It is therefore critical that CCGs ensure that they have processes in place for meeting the health needs of all these children and young people.

2.2 Local leadership and partnership working

Every Clinical Commissioning Group (CCG) must have an executive or board-level officer responsible for ensuring CCG compliance with the SEND framework, who reports to the executive (CCG Governing Board, Executive or Senior Leadership Team). This is essential for ensuring that disagreements relating to the responsible commissioner, and specific commissioning requests, can be resolved appropriately. SEND must be a key priority within CCG commissioning intentions, and the needs of this group must be reflected in commissioning.

CCGs should consider how they can use the [NHS Standard Contract 2017-19](#). The [particulars](#) page 24 refers to section G (Other Local Agreements, Policies and Procedures), which ensures that commissioners make sure their providers support them in their responsibilities. It can also be used to record agreements reached on other matters that do not conflict with the Contract, such as specific behaviours/actions to support joint working arrangements.

Local areas may wish to make use of NHS England [Developing support and services for children and young people with a learning disability, autism or both](#) published in September 2017.

Partners represented on the local Health and Wellbeing Board (HWB) may wish to consider the population needs for SEND when reviewing and revising their Joint Strategic Needs Assessment (JSNA) and Joint Health and Wellbeing Strategy (JHWS).

Under the **Local area special educational needs and disabilities inspection framework**, Ofsted and the Care Quality Commission (CQC) review how local areas meet their responsibilities to children and young people (from 0 to 25) who have special educational needs or disabilities (or both). The Inspection reports published up to 22nd March 2017 are available [here](#). Those published after this date can be found [here](#).

3 Clinical Commissioning Group role

Role	How do you know if you are getting it right?
<p>Local Offer</p> <p>The CCG must work with the LA to develop a Local Offer co-produced with children and young people with SEND and their parents, covering support available for those with SEND, both with and without EHC plans</p> <p>All LAs should have a Local Offer on their website.</p> <p>Joint arrangements require a mechanism to ensure health information is comprehensive and up-to-date, and for keeping it under review.</p>	<p>The local offer has links to the CCG website.</p> <p>The local offer has clear descriptions of the health services available, who provides them and how to refer to, or access, these services.</p> <p>Feedback from service users is positive on the information available.</p>

Joint commissioning arrangements

The CCG must participate in joint arrangements with the LA for considering and agreeing provision for children with SEND. The LA will lead the co-ordinated process for assessing the needs of a child with SEND, and developing the EHC plan; the CCG must ensure that the agreed health services are initiated.

A Section 75 arrangement or Section 256 agreement provides the legal powers to formalise joint commissioning arrangements, which can also include pooled budget arrangements. **Options for Joint Commissioning. Beyond Barker (King's Fund, 2015)** discusses joint commissioning options.

4 bulletins have been provided by the Council for Disabled Children (CDC) to support local areas with delivery of the SEND reforms. These focus on:

- identifying the responsible CCG commissioner
- core functions of a speech and language therapist, occupational therapist and physiotherapist
- applying an outcome-based approach to commissioning
- promoting personalisation and access to personal budgets.

There are joint commissioning arrangements in place or planned.

There is a clear decision-making pathway and/or panel process in place for joint funding arrangements.

Local areas may wish to refer to the following guidance

- **Supporting pupils with medical conditions at school - DfE - Updated Aug 2017**
- **Who pays? Determining responsibility for payments to providers NHS England Aug 2013**
- **Manual for prescribed services 2017/18 NHS England**

EHC assessment process

Each CCG should work with the LA to develop an EHC plan for each eligible child with SEND. A case worker will co-ordinate the assessment, and will contact health services for their input. This input might range from providing a written report based on the child or young person’s current health status, to a professional such as a paediatrician or a therapist participating in a multi-disciplinary assessment.

Joint arrangements between the LA and the CCG should consider how the right services can be identified, how contributions to plans will be commissioned, and pathways for undertaking new assessments.

The Designated Medical or Clinical Officer will play a key role in ensuring effective arrangements are in place.

Use of the [Children and young people’s continuing care national framework DH](#) Updated Jan 2016

All providers have a SEND named point of contact for EHC plan assessment requests.

All providers are clear on the EHC plan assessment process and timescales.

There is agreement between the LA, CCG and providers on when and how health services will engage, depending on whether the child is known/not known, or was known and has been discharged.

Joint monitoring including data on timeliness of provision of advice and support shows that things are going well.

Feedback from service users. As set out in the SEND accountability framework, local areas are expected to collect feedback from children, young people and their families and use this to improve services and delivery.

Health care provision

The health care provision specified in the EHC plan must be agreed by the CCG and any health care provision should be agreed in time to be included in the draft EHC plan sent to the child’s parent or to the young person.

There are clear decision-making pathways and/or panel processes in place for joint funding arrangements.

4 Designated Medical Officer or Clinical Officer role

4.1 Overview of the role

The Designated Medical Officer (DMO)/Designated Clinical Officer (DCO) provides the main point of contact for local authorities (LAs), schools, colleges and early years settings that are seeking health advice on children and young people who may have SEND. They can also have a wider role in relation to supporting the process.

A DMO/DCO can support the CCG in meeting its statutory responsibilities in relation to SEND. Partners should ensure that there is a clinician fulfilling this function. Whilst it is currently a non-statutory role, Ofsted and CQC have identified this role as an important factor in the implementation of the Children and Family Act reforms. NHS England SEND programme is planning to review the learning, impact and function of these roles in 2018/19.

4.2 Local considerations re strategic and operational functions

The SEND inspections and DMO/DCO networks have highlighted the variation in local interpretation and recruitment of these roles. There may be one DMO/DCO for several CCGs and LAs, where there are joint arrangements or shared commissioning responsibilities. As the age range of an EHC plan is from 0 to 25, the DMO/DCO will need to have links to adult services as well as paediatrics.

The DMO/DCO should have an appropriate level of clinical expertise to be able to operate effectively, and should be designated as the DMO DCO in their job description, with dedicated Programmed Activity. It is unlikely that this role can be effective without sufficient Programmed Activity allocated to it.

The CCG as a commissioner has to make sure that the services it has commissioned are responsive and appropriate. This may not require more than a contractual acknowledgement that relevant staff, paediatricians, nurses and therapists are responsive to requests for information or participation in a multi-professional assessment, and otherwise supportive of joint arrangements.

A CCG may wish to agree a more detailed, albeit relatively generic, specification as part of its contracting, so that expectations, and the form of the monitoring process, are clear.

A CCG may need to commission additional Programmed Activity (PA) sessions from an NHS provider, to undertake the functions of a DMO, and/or commission additional activity to undertake the functions of a DCO. This is best done by working with the provider to agree the necessary changes to an existing service specification, and formalising this through a contract variation.

Alternatively, the CCG may choose to employ a DMO and/or DCO. In this instance, it is recommended that the CCG reviews nationally available job descriptions for these roles as part of the planning and recruitment process.

More generally, the CCG should ensure a mechanism is in place for providers to liaise directly on individual funding requests, or to highlight other issues or gaps in services, which might prevent the CCG from delivering on its statutory requirements. The DMO or DCO could exercise this link role and might also be able to broker discussions between providers, or the local LA, in agreeing on these issues.

4.3 Additional support for designated officer roles

The DMO/DCO should also ensure they are in touch with relevant leads in the LA (or other authorities) that oversee the EHC plan process, and can advise local health professionals on where key information can be accessed. CDC runs a forum for DMOs and DCOs which enables them to share queries and information. To join the online forum, please email your request to cdc@ncb.org.uk.

CDC have produced a [handbook](#) on the role of the DMO and DCO which sets out practical tips and learning for DMOs and DCOs, commissioners and other professionals involved in the implementation of the health elements of the [Children and Families Act 2014](#).

5 Education, Health and Care plan

Each LA has a statutory responsibility for leading the EHC plan process supported by joint arrangements between LAs and CCGs. The local LA must gather advice from relevant professionals about the child or young person's education, health and care needs, desired outcomes and any special educational, health and care needs, in order to meet them effectively.

Each LA must have commissioning arrangements in place with their relevant CCGs, in line with the requirements of the [Children and Families Act 2014](#) for special educational needs. Where the CCG or a LA is acting as lead commissioner for children, it should ensure it publishes the arrangements on the Local Offer website; ideally all stakeholders should be involved at an early stage in the development of these arrangements.

The CCG must ensure that any provider of health services that it commissions is fully informed about the new arrangements, so it can respond effectively when asked for advice or to participate in an EHC plan assessment.

The [NHS Standard Contract 2017/19 updated May 2018](#) now states that where a LA requests the cooperation of the Provider in securing an Education, Health and Care Needs Assessment, the Provider must use all reasonable endeavours to comply with that request within 6 weeks of the date of receipt. This can be found on page 13, (Ref 10.5) of the [Service Conditions](#).

Providers might include: local Foundation Trusts and NHS Trusts providing paediatric services, therapies and other clinical services; community nursing teams; and hospices and palliative and respite care providers. Key professionals in these services are likely to be aware of the SEND arrangements nationally. However, implementation will only be effective if the process for involvement is clear.

The SEND assessment must cover:

- the format of the EHC plan being used locally
- who will be requesting information from health professionals about a child or young person: this might be a communication direct from a LA, or could be routed via a single contact point in the CCG or the provider – any relevant professional should familiarise themselves with the request process
- procedure within the CCG, for signing off significant health advice

- the format for returning health advice (see below)
- the timescales for returning advice (within 6 weeks of a request being made)
- how professionals can input to multi-disciplinary team or co-ordinated planning meetings
- a request for input to an EHC plan issued by a local LA should be largely self-explanatory to a clinician not previously involved in the process, and should have contact details where more information can be sought.

EHC plans

CDC has developed **guidance** to support LAs, CCG's and NHS trusts to set up processes that facilitate the provision of good health advice as part of an EHC Needs Assessment.

6 Health contribution

Depending on the needs of the child or young person and the care they require, a number of different professionals may need to be involved: paediatricians, community children's nurses, allied health professionals, mental health professionals, psychologists, general practitioners, school nurses and health visitors.

Professionals should work in co-production with the family of the child or young person. Families will be able to share with the LA the child or young person's history, and the details of professionals involved in their care.

In some cases, this may not be easily accessible, and a LA may need to refer to the CCG for the most appropriate route for a request. For example, for a child or young person with a serious neurodisability, newly arrived in the area, a request to a local paediatric team would be appropriate.

As part of joint arrangements agreed between the CCG and the LA, where there is minimal information on a child or young person's needs, or on the professionals who are caring for them, it would be sensible to agree how health requests will be routed. It is unhelpful for a LA to need to guess which service it should contact.

6.1 Early identification

Children with additional or complex health needs often require additional support to ensure a seamless transition into school, and that they feel supported to learn within an education setting.

Health visitors and school nurses lead the delivery of the **Healthy Child Programme (HCP)**; as such they often have ongoing relationships with children, young people and their families. They can provide early identification of health issues, and support specialist referrals. The 4-5-6 model that describes how health visitors and school nurses deliver the HCP is a useful visual resource, and can be accessed [here](#).

The benefits of early identification of SEND are widely recognised: identifying need at the earliest opportunity, and then making effective provision, improves long-term outcomes for children. Health professionals have an important role to play in early identification through neonatal **screening programmes**.

It is important that there is a focus on the needs of children and young people and ensuring children are school ready within:

- mainstream education, for those with additional health needs, for example mobility issues, asthma or continence (bladder or bowel) problems
- special schools, for those with complex health needs, for example a child with respiratory support needs or complex learning disabilities.

Health professionals who are involved, or might become involved, in the care of this group will need to be aware of the new arrangements nationally, and their local implementation.

CCGs and NHS Trusts must inform the appropriate LA if they identify a child under compulsory school age as having, or probably having, SEN or a disability (**Section 23 of the Children and Families Act 2014**).

6.2 The beginning of the EHC plan process

The **Children and Families Act 2014** is a framework for co-operation: the key to effective and smooth-running assessments is co-operation on the processes that inform assessments, and establishing effective lines of communication.

A health service or a health professional might be asked to contribute because they have a role in the child or young person's care, for example, a paediatrician who is already seeing the child or young person, or a therapist providing sessions of therapy. Alternatively, they might have a potential role, for example, where a child or young person is suspected of having a special educational need and might be expected to be seen by the child development team or similar.

Health professionals must restrict their advice to their area of expertise, and must not make recommendations about specific educational placements. Where the parent of a child with SEN, or a young person with SEN, wants a place in a mainstream setting it must never be denied on the basis that this setting is unsuitable, or that their needs or disabilities are too great or complex. Health professionals need to be prepared to work with all settings, specialist and mainstream, to ensure that children's health needs are met appropriately.

All of the CDC resources referred to above aim to support LAs, CCGs and NHS Trusts to set up processes that lead to good health advice, supporting EHC plans that meet both the letter and the spirit of the **Children and Families Act 2014**.

6.2.1 Requesting advice if known to services

Where a child or young person is already known to a professional or team, it should be relatively straightforward for a professional to:

- provide an opinion, based on the young person's history, case notes, and the professional's experience
- participate in a multi-professional discussion on the child or young person's needs, and the outcomes that would make the most difference to them.

Those teams that have most contact with children with special educational needs will want to ensure they are able to respond effectively to requests for information, or assessments.

It may help a provider (or a relevant team within a provider) to have a single point of contact or receipt for requests, and for relevant LA SEND teams to be advised of this. Such an approach would need to be aligned with other referral routes, such as from GPs. This would allow a team to take stock regularly of incoming requests, ensuring they were dealt with consistently and appropriately.

Some clinicians may have been involved in providing care for a child or young person outside a Trust or other organisation - for example, as an independent therapist - and receive a request directly. Where a clinician is part of a larger organisation, and receives a request, they should check with the clinician responsible for providing advice, on whether there are arrangements in the organisation for handling, or auditing, such requests.

If a service or a professional has not undertaken an assessment of a child, but they are known to them - for example, the service has received a referral - then the service needs to decide whether the assessment can feasibly be undertaken within the timeframe, without compromising the principles of fairness and equality to all children and young people on a list.

6.2.2 Requesting advice if not known to services

Paediatricians may receive a request for health advice relating to a child with whom they are unfamiliar. This may be a logistical issue, e.g. the LA or CCG routinely contacts particular paediatricians for advice, or requests are routinely routed via a particular team.

Professionals will need to decide how to respond to such requests, satisfying themselves that advice is being sought from other appropriate professionals, and that the child or young person does not require their attention. They should seek as much information as possible, so that an informed decision can be made.

Where a child is completely unknown to a service or professional, it may not be appropriate for an assessment to be undertaken, or for advice to be provided, beyond written notice to the LA that it is not possible to comply. This would be reasonable where the request appears to have been made of the wrong service, or where there is no evidence that the child or young person is suitable for referral. In these cases, there should be a system enabling professionals to raise their concerns, or obtain more information on the individual, e.g. from the LA. Some DCO/DMOs are attempting to triangulate evidence, and telephoning parents to see if there are any unmet health needs.

When a child is likely to need an assessment or to receive services, it would be valuable if different partners could agree arrangements for facilitating the appropriate referral. In many cases, a child or young person will need an assessment of clinical need, and a referral would place them on a pathway for assessment. Annex A provides a possible framework for decision-making in such cases.

Some services, in planning sessions, have deliberately retained slots for providing short-notice assessments, although this becomes logistically more complicated where a multi-professional assessment is needed. Where there are significant waits for an assessment, it may be reasonable to provide some initial advice, with the fuller assessment ideally taking place within 12-14 weeks, so that the EHC plan is completed within the statutory timescale.

6.3 Health Role in meeting the requirements of advice within 6 weeks

One of the key aims of the statutory framework in the **Children and Families Act 2014** is a more timely response to children's needs. The Act therefore requires those partners of LAs who receive a request for information to support an assessment, to comply within 6 weeks. The only exception is where the person or body to whom the request is made considers that to do so would:

- be incompatible with the duties of the person or body, or
- have an otherwise adverse effect on the exercise of the functions of the person or body.

Where a person or body decides not to comply with a request, they must give the requesting authority written reasons for the decision.

Note that complying within 6 weeks does not necessarily mean a full assessment has been carried out within 6 weeks, as this may be neither clinically appropriate nor necessary. Health professionals should, however, ensure that within that timescale, all relevant information can be provided. Further information regarding Health Advice within 6 weeks can be found [here](#).

6.4 Working with other professionals around the child and family

6.4.1 Mental health

Cross referral to other services, such as Child and Adolescent Mental Health Services (CAMHS), may also be appropriate, in line with the established routes of referral. Some CAMHS services will likewise have a generic mailbox or similar route through which requests are channelled. In some providers, a request is first subject to a preliminary review; a simple checklist could be developed for considering the evidence supplied, and should include any relevant data drawn from clinical systems.

6.4.2 Health visiting and nursing

Each health visiting and nursing role has its own unique contribution to make for children and young people with SEND. Table 1 highlights these complementary roles within the context of locally-determined commissioning arrangements.

Table 1 – Health Visiting and Nursing roles in relation to children and young people (0-25 years) with SEND

	Health Visiting and School Nursing Teams	Special School Nurse	Community Children’s Nursing Teams	Learning Disability Nursing Team
	Commissioned by Local Authority	CCG (Locally determined)	CCG (Locally Determined)	(Locally determined)
Roles and areas of work	<ul style="list-style-type: none"> • Leading delivery of the HCP 5-19 • Referring to specialist services according to locally-agreed pathways • Co-ordination and training for schools regarding additional health needs (Local Determination) e.g. asthma and anaphylaxis training • Supporting the development and review of Education Health and Care (EHC) plans • Advising on management of medications in school in accordance with Trust and DfE policies, and developing staff training programmes, in partnership with school staff. 	<ul style="list-style-type: none"> • Supporting health and wellbeing by providing care and/or by referral or signposting to other services • Carrying out an annual health review and care planning for all children in school, in partnership with other health disciplines • Supporting, and providing guidance for, the school, child, young person and family when developing individual care plans • Advising on management of medications in school in accordance with Trust and DfE policies, and developing staff training programmes, in partnership with school staff • Contributing to the management of transition to adult services. 	<ul style="list-style-type: none"> • Providing specialist clinical nursing advice and interventions for children with: <ul style="list-style-type: none"> • long term conditions • disabilities and complex conditions • life-limiting and life-threatening illness • acute and short term conditions • Assessing, and advising on, the nursing needs and outcomes for each child’s EHC • Providing clinical training for school staff aligned to the child’s EHC. 	<ul style="list-style-type: none"> • Supporting health and wellbeing by providing care and/or by referral or signposting to other services • Carrying out an annual health review and care planning for all children in school in partnership with other health disciplines • Supporting, and providing guidance for, the school, child, young person and family when developing individual care plans • Contributing to management of transition to adult services • Advising on access and individualised reasonable adjustments • Positive behaviour support • Training, and provision of advice, on specific clinical conditions, such as autism and autistic spectrum. disorders

7 Engaging with families

7.1 Supporting and involving children and young people

Under the general principles within **Section 19 of the Children and Families Act 2014** states LAs must pay particular attention to:

- the views, wishes and feelings of children and their parents, and young people
- the importance of these parties participating as fully as possible in decision-making and providing the information and support to enable them to do so
- supporting children and young people's development and helping them to achieve the best possible educational and other outcomes.

It is important that the CCG as LA partner in the delivery of the reforms also gives priority to these principles in the way that they work with children and families.

The assessment of a child or young person's needs should be undertaken in partnership with them and their family, and should be guided by their views, wishes and feelings.

The liaison of CCGs and LAs in planning and securing services, and providing advice and information on those services to the local population, will only be effective if children, young people and their families are involved. Where children, young people and parents feel they have participated fully in the process and have a sense of co-ownership, this is often referred to as 'co-production'.

The views of children, young people and their families should be included in every CCG and provider engagement plan. In almost every LA area there is a parent carer forum, whose membership is made up of parents of children with a range of disabilities and conditions. They work in partnership with commissioners to make sure that suitable services are commissioned, and help them monitor how well these services are being provided.

Contact (a network for families with disabled children) supports the work of parent carer forums; its website has many examples of how forums have helped improve services and resources. **The National Network of Parent Carer Forums (NNPCF)** is made up of all of the parent carer forums from across England. Both websites have contact details for all forums.

7.2 Opportunities to involve parents/carers

Opportunities for involving parents/carers in the CCGs arrangements include:

- developing the scope of Personal Health Budgets
- developing guidance for Health input into EHC plans
- writing accessible guidance on both the above, including sourcing and drafting case studies
- developing and delivering joint training
- parents and young people presenting the impact of decisions on families
- participation in procurement exercises (e.g. developing specifications)
- facilitating stakeholder consultations, especially giving end user views
- taking an equal place on a commissioning panel

- development, articulation and review of DMO/DCO role
- recruitment of DCO and other family-facing roles.

7.3 Examples of working in partnership with parents

There are many examples of how parent carer forums are working with their local health services, some of these can be accessed at [Contact: Success Stories](#). There is also information on [Community Grants Projects](#) on the NHS England website.

7.4 Information, Advice and Support Services

A CCG will want to consider with its LA how real-time advice can be accessed by young people and their families. A single-point of access for information on services, or on the EHC process, even if organised by the LA, must be supported by the CCG. Alternatively, the CCG should ensure that their own information, advice and support provision connects with that provided by the LA.

All LAs have Information, Advice and Support Services (IASS) (formerly known as Parent Partnership services) in relation to SEND. Services provide advice and support to parents and direct to young people themselves, and are expected to cover education, health and social care information.

These services are key to enabling individual participation, by ensuring that young people and their families have the information they need to help them make decisions about the services and support they receive. Since the IASS has broadened its remit, some CCGs are jointly funding their local IASS. Visit the Information, [Advice and Support Services Network website](#) for more information.

In line with other aspects of a CCG's role, it is useful to provide proactive information on SEND, via leaflets and outreach in key settings. This is essential in settings such as special schools, children's centres, and outpatient departments. Monitoring the volume and content of requests for advice or of complaints is an important indication for a CCG of key issues or pressures, and the efficacy of the CCG role.

7.5 Complaints

Complaints in relation to health services for a child or young person with SEND might be made direct to the CCG, or its partner LA, or to the relevant provider. The partners in the joint arrangements will need to consider how complaints made via different routes can be brought together.

Joint arrangements should include a mechanism for ensuring that complaints are dealt with appropriately. The onus should not be on the complainant to navigate a complicated process; the Local Offer should set out how complaints can be made, and how they will be handled, including details of timescales.

7.6 Mediation and first tier tribunal trial

CCGs are required to ensure they offer independent mediation in relation to the health element of an EHC plan, in terms of user satisfaction. LAs have a similar responsibility in relation to the educational element of the plan. Partners in the joint arrangements could use a common approach and provider.

The First-tier Tribunal SEND hears appeals against decisions made by LAs in England in relation to children and young people's EHC needs assessments and EHC plans. At the moment, the powers of the First-tier Tribunal SEND in relation to EHC plans are limited to the educational aspects of the plan.

The Department for Education will launch a two-year national trial on the 3rd of April 2018 to **extend the powers of the Tribunal** to make non-binding recommendations on the health and social care elements of EHC plans.

The trial will enable the Tribunal to take a more holistic view of children and young people's needs across education, health and social care, in line with EHC plans. A process evaluation will run alongside the trial to assess the impact on children and young people with SEND, and on the education, health and social care sectors, to inform a decision on future roll out.

The trial will place responsibility on LA SEND teams to:

- inform parents and young people of their new rights, including through decision letters and the local offer
- contact the relevant health or social care lead about the issues raised, and provide evidence to the Tribunal on their response
- send the health or social care response to the recommendation to the evaluators, once a decision has been made.

It also places responsibility on health and social care commissioners to:

- attend the hearing if required, and respond to any request for information, such as any assessments or information about support provided
- respond to the family and the LA within 5 weeks of the decision, setting out the steps they have decided to take or why they are not going to follow the recommendation.

For further information:

[Single route of redress national trial \(Toolkit\)](#)

[SEND Tribunal single route of redress national trial: Guidance of local authorities, health commissioners, parents and young people \(Guidance\)](#)

8 Data sharing

There are several aspects to sharing data between organisations involved in the SEND process. Colleagues are recommended to speak to the Information Governance function of their organisations for the latest advice of data sharing.

8.1 Patient Communication and Engagement

A key element to appropriate data sharing is to make sure that patient's, their parents and carers, are aware of how their data will be shared and used. An ongoing programme of patient communication tailored for the specific needs of the patient cohort is a crucial part of meeting the legal obligations of SEND partner organisations.

8.2 Processes and Governance

There are several processes that are recommended to support data sharing between organisations. These are:

- Privacy Impact Assessment – looking at the risks to privacy, the controls in place and any gaps
- Data Flow Mapping – analysing the flows of data, to ensure that responsibilities are properly mapped and management
- Data Sharing Agreements – an agreement between data controllers setting out how they will manage their obligations to each other to ensure that patient data is shared lawfully, appropriately and within a clear operational framework

There is guidance available on each of these practices from the Data Protection regulator, the Information Commissioner's Office, within the Information Governance Toolkit, and from the Information Governance Alliance.

Organisations should also consider what governance is required to supported and develop ongoing data sharing practices as part of developing their SEND services.

8.3 Security

Ensuring that data is shared securely is an important aspect. Any health and care organisation wishing to operate its own email systems securely and connect it to other secure email services such as NHSmail to be part of the health and care sector wide secure communication environment must meet the **Secure Email Standard** published in March 2014 by the Information Standards Board.

However, there is also an encryption feature which means that NHSmail users can securely exchange sensitive information with users of non-accredited or non-secure email services, for example those ending in Hotmail, Gmail and Yahoo.

The NHSmail encryption feature means that health and social care staff now benefit from a secure service which allows them to communicate across organisation boundaries and industry sectors. NHSmail can now be used securely across the entire health and social care community using any email account. This feature will allow health professionals to submit their contributions to EHC plans, and to discuss cases involving confidential data, by email.

- For a step-by-step guide for senders in the NHS see **[Sending an encrypted email from NHSmail to a non-secure email address \(January, 2015\)](#)**
- For recipients, see **[Guidance for recipients of an encrypted NHSmail email \(January, 2015\)](#)**
- Further information on the **[encryption feature](#)** in general
- A guide to confidentiality in health and social care. **[Treating confidential information with respect \(HSCIC, 2013\)](#)**
- Further resources to support safe and effective information sharing can be found at the **[Centre for Excellence for Information Sharing](#)** and the **[Information Governance Alliance](#)**.

Other means of sharing information will need similar consideration to ensure they maintain the same standard of security.

9 Community Services Data Set

NHS Standard Contract 2017/18 and 2017/19 refers to the Children and Young People's Health Services (CYPHS) dataset on page 80-81 of the [technical guidance](#).

Providers of clinical care to children with disabilities should be aware of the role which the [community dataset](#) can play in helping to build up a better picture of these disabilities and complex needs across the country. The data helps CCGs to assess wider population needs and commissioning of services locally. Other relevant data sources are outlined in the Council for Disabled Children's report [Understanding the needs of disabled children with complex needs or life-limiting conditions](#).

The community services dataset includes:

- personal and demographic information
- social and personal circumstances
- breastfeeding and nutrition
- care event and screening activity
- diagnoses, including long term conditions and childhood disabilities
- scored assessments.

Clinicians can capture information on all the needs of a particular child or young person, as an 'electronic medical record'. A unique [glossary](#) has been developed, using Systematized Nomenclature of Medicine – Clinical Terms code. (SNOMED CT)

Once recorded in the electronic medical record, data can be sent to the provider's data hub or repository, and be included in the mandated monthly report to NHS Digital for the dataset.

The Community Services Data Set came into force on the 1st October 2017, and incorporates the CYPHS dataset. NHS Digital will now be able to report data on community services for adults, supporting the collection of SEND data from 0-25yrs. Further information on the transition to the new data set can be found [here](#).

Further information on the Children and Young People's Health Services dataset:

[The British Academy of Childhood Disability](#) has identified actions for providers to support this data collection, and has links to supporting information.

NHS England has published a blog by Dr. Karen Horridge, '[Data matters for disabled children, young people and their families](#)'

[NHS Digital Newsletter](#)

10 Patient Choice

There are a number of organisations involved in the development and delivery of an EHC plan, and they will need to set out a basis and means of sharing data between parties.

As the local authority is usually leading the process for the EHC assessment, they would usually obtain early agreement from children, young people and their families for the sharing of confidential information with a suitably comprehensive form. Health providers or commissioners need to assure themselves that any such legal basis for sharing is appropriate, and satisfies their own policies in relation to data protection and confidentiality

With the advent of the General Data Protection Regulations (GDPR) and the associated UK Data Protection legislation, organisations need to be clear that their use of consent is appropriate and meets the required standard. Organisations are recommended to ensure they are up-to-date with the latest guidance from the Information Commissioner's Office (ICO) and the Information Governance Alliance on the issue. Key is for those delivering SEND to understand and clearly set out the choices available to patients and how those choices will be exercised.

Examples of consent forms

[Southend EHC Parental Consent Form](#)

[Birmingham City Council Consent to Request for Statutory EHC Needs Assessment](#)

Children and young people may refuse their consent if deemed to be 'Gillick' competent, e.g. they are able to demonstrate the maturity and intelligence to understand the implications of giving consent. They can also withdraw their consent at any time. In the case of an EHC plan, this may prevent key information from being considered, and this should be made clear to the child or young person and their family, when the plan is being discussed. It is important that people know the impact of the withdrawal of consent.

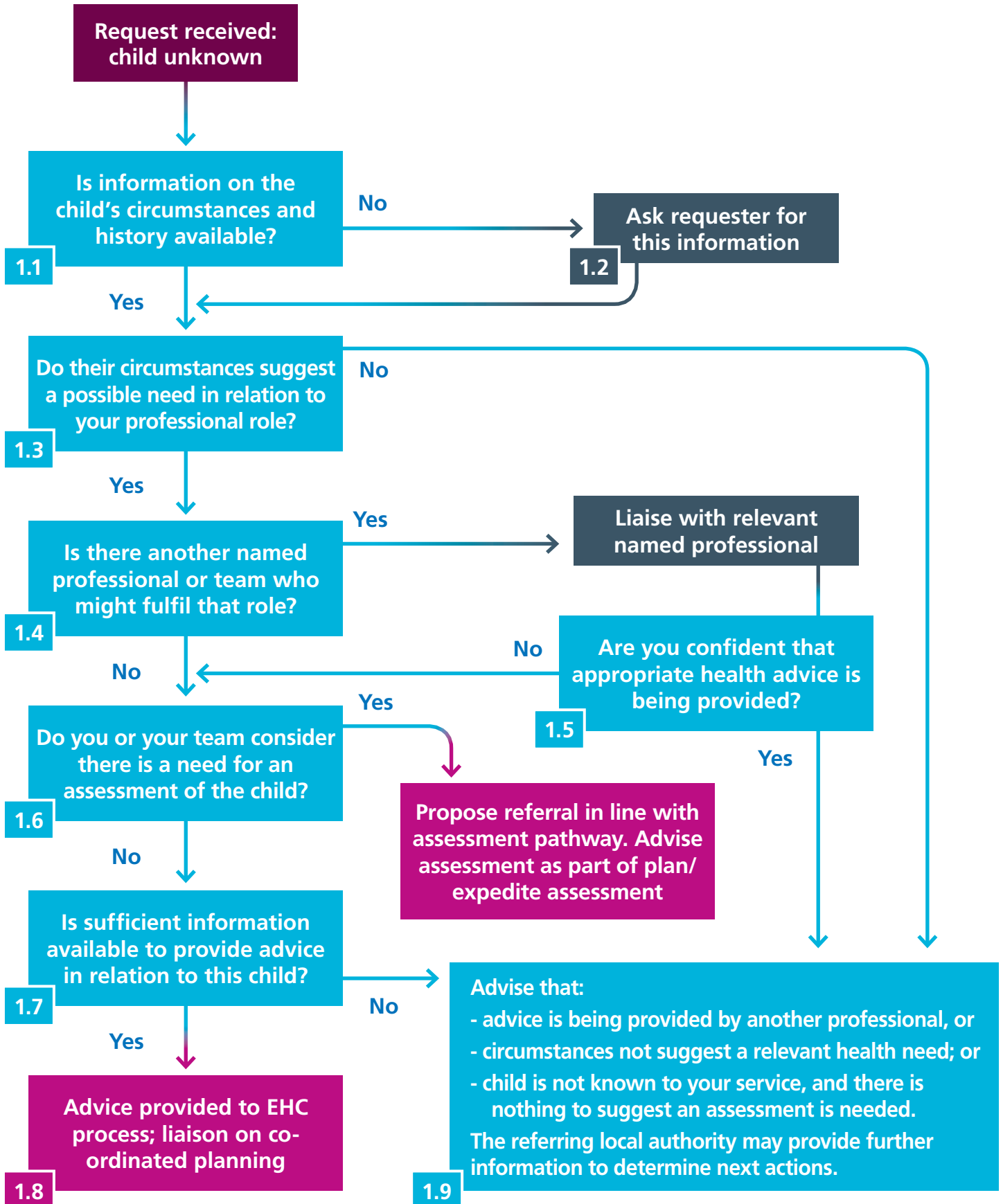
There will be exceptions to this rule: for instance where sharing information is necessary for safeguarding children and young people, or where it is legally required by the courts or the police.

If a child under 16 does not have the capacity to give consent, someone with parental responsibility can consent for them, provided they have the capacity to give consent. Under the [Children Act 1989](#) a person with parental responsibility for a child or young person could be:

- the child or young person's parents
- the child or young person's special guardian (under a special guardianship order)

- the child or young person's legally appointed guardian
- a person named in a child or young person's arrangements order as a person with whom the child or young person is to live
- a LA designated to care for the child or young person (under a care order)
- a LA or person with an emergency protection order for the child or young person.

11 Annex A: Process for requests where the child is not known to clinicians



Notes to support Annex A

- 1.1 Requests for advice should usually include detailed information on the child or young person; some EHC plans have been designed to be internet-accessible to any relevant professional who needs input.
- 1.2 If the child or young person is not known to you or your team, it would be reasonable to request more information – for example, a parent may have requested an assessment of their child. This might also provide a basis for a discussion about the advisability of routine referrals, particularly to paediatrics.
- 1.3 There may be no reason, based on the information provided, why you or colleagues would provide advice, and it might be appropriate at this point to provide a brief confirmation that the child or young person is not known to you.
- 1.4 Duplication should be avoided. For example, if an occupational therapist receives a request for advice, but it is clear that a child or young person is already under the care of another, it would be appropriate to refer the requester to that professional instead. Alternatively, you might wish to liaise directly with that professional.
- 1.5 This should allow you to determine if the appropriate advice relative to your role is being provided. Where this is the case, a brief notification to the LA to this effect should be provided, ideally specifying the source.
- 1.6 If there is a potential need for professional input, and no one else appears to be providing this, you should consider whether or not you or your team should see the child or young person, or provide advice.
- 1.7 Where a referral would be appropriate, this should be advised, in line with the local pathway; it may not require a referral from a school or GP. Health advice should be given to this effect, proposing an assessment as an action for the EHC plan.
- 1.8 Alternatively, information may be available - from clinical systems, such as System One, or from the requester or other professionals - which suggests there is no need for an assessment, due to the child or young person's age or development, but which allows for the provision of health advice to the EHC plan process. Where this advice is given, it should be made clear that the child or young person has not been assessed by you or your team, and that an assessment is not thought to be necessary.
- 1.9 It may also be the case, having considered all options, that the most appropriate advice remains that the child or young person is not known to you or colleagues, and there is nothing to suggest that your professional input is needed.