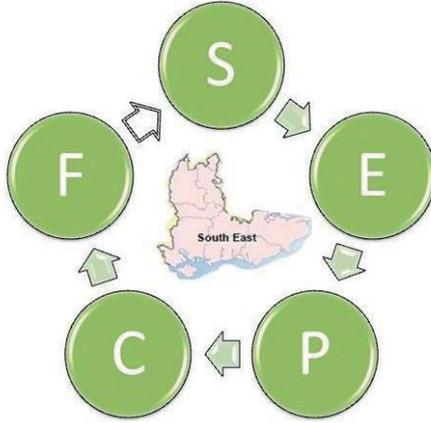


A GUIDE TO SUPPORT PARENT CARER FORUMS IN THE SOUTH EAST

Demystifying the **NHS**



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The Health & Care Act 2022 officially approved Integrated Care Systems (ICS) to unite health and care and reduce health inequalities.

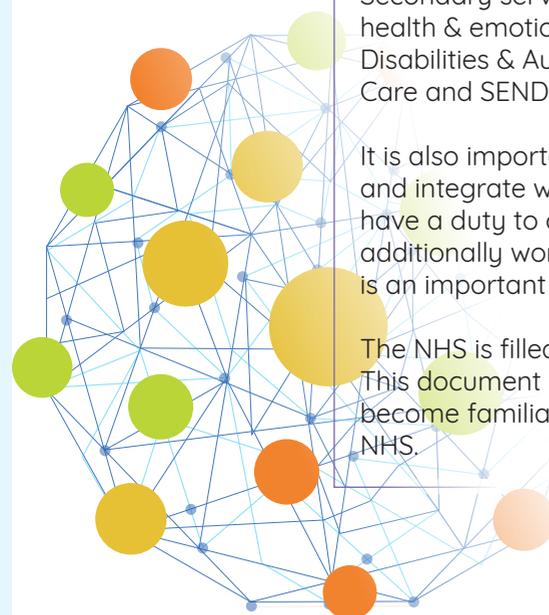
This brings about radical change to how NHS health services are commissioned and how they will work together with local partners. There is now a statutory duty to engage with patients and the public and to collaborate as a system to deliver health and care.

This document gives a brief overview of the NHS focusing on the latest reforms. It explains what Integrated Care Systems (ICS) are, their structure, how they should operate. How the Integrated Care Board (ICB) and Integrated Care Partnership (ICP) that sit below them to develop a health strategy and delivery plan for each ICS. ICPs membership includes Local Authority (LA), Healthwatch, clinical leads, voluntary community or social enterprise organisation (VCSEs) and other partners.

In each ICS the ICBs now become commissioner and funder of many local health services. Explained are the health services and organisations that provide them. Highlighted are some of the key areas for Forums including the Healthy Child Programme, Targeted & Secondary services, Thrive model to deliver mental health & emotional wellbeing services and NHS Learning Disabilities & Autism programme including Transforming Care and SEND agendas.

It is also important to understand how NHS services work and integrate with the LA and VCSEs. LAs continue to have a duty to commission Public Health services but now additionally work with ICSs to plan and deliver them – this is an important part of the picture to understand.

The NHS is filled with acronyms, language and jargon. This document deliberately uses jargon so you can become familiar with it and help you working with the NHS.



Introduction



The National Health Service (NHS) was started on 5th July 1948 by Labour Health Minister, Aneurin Bevan.

The newly created NHS was set up to provide free healthcare, at the point of use, based on need and not means, for everyone from 'cradle to grave'.

This remains the ethos of the NHS but increasing cost and complexity in healthcare mean some elements of health care have a cost unless eligible e.g. prescriptions, dentistry.

The NHS is the largest single health system in the world employing more than 1.4 million people; there are currently 215 NHS Providers (large organisations that deliver health care to patients) and 6,500 GP surgeries. Everyone works to the same [NHS Constitution](#) and the [NHS Mandate](#) from the Secretary of State (as the head of the Department of Health & Social Care). NHS England leads the entire NHS to deliver services for all and sets direction in The [Long Term Plan](#). NHS England has many 'programmes of work' to set strategy, address a national need, support and train the workforce.

The latest NHS reforms in the Health & Care Act 2022, change the organisation and commissioning, as well as behaviour of health services in England. For Forums to be effective partners in the system, and advocate for their members, it is helpful to have an overview of the ENTIRE health system and most specifically health services for children (0-19) and then transition from children to adult services (18 or 19-25).

[NHS Health and Care Act 2022](#) brings top-down reform about improving health outcomes by joining up NHS, social care and public health services (integrating care) at a local level and tackling growing health inequalities. It is focused on **developing system working** by clearly setting up **strategic collaboration, partnerships** and **partnerships working**. This is a radical change to organisational structures and system behaviour.



The Health & Care Act 2022

The Health & Care Act 2022 is about collaboration and partnerships in contrast to competition and 'silo working' of the past. The main features are summarised here.

Health & Care Act 2022 top-down reforms creating ICSs

NHS England now gives funding to 42 newly created **Integrated Care Systems (ICSs)** aligned to county council boundaries. Each ICS has a statutory **Integrated Care Board (ICB)** working with its **Integrated Care Partnership (ICP)**.

The **Integrated Care Board (ICB)** is the statutory NHS organisation responsible for

- developing a plan for meeting the health needs of their population,
- managing the NHS budget and
- arranging for the provision of health services in the ICS area.

ICBs replace Clinical Commissioning Groups. ICBs now fund GP Surgeries and also have delegated commissioning responsibility for NHS dentistry, community pharmacy and ophthalmology.

ICB's must work to ensure **system financial balance**.

Integrated Care Partnership (ICP) is a broad alliance of partners concerned with improving the care, health and wellbeing of the population, with membership determined locally. The ICP is responsible for producing an integrated care **strategy** on how to meet the health and wellbeing needs of the population in the ICS area. ICP's are made up of ICB members, local authority, Healthwatch and other partners.

NHS Provider collaboratives work to reduce place-based health inequalities and to achieve benefits of working at scale.

Healthwatch is part of the ICP.

Public Health these statutory duties remain with the Local Authority

NHS England & NHS Improvement have merged (and **NHS Digital** and **Health Education England** are closer aligned in NHS England)

ICSs are about strategic collaboration, partnerships and partnerships working.

Integrated Care Systems (ICSs)

The purpose of ICSs is to bring partner organisations together to tackle complex challenges.

- improve outcomes in population health and healthcare
- tackle inequalities in outcomes, experience and access
- enhance productivity and value for money
- help the NHS support broader social and economic development in that area.

To tackle complex (population) challenges, including:

- improving the health of children and young people
- supporting people to stay well and independent
- acting sooner to help those with preventable conditions
- supporting those with long-term conditions or mental health issues
- caring for those with multiple needs as populations age
- getting the best from collective resources so people get care as quickly as possible

In South East England, the Integrated Care Systems are:

Buckinghamshire, Oxfordshire and Berkshire West - **BOB ICS**

Hampshire & Isle of Wight (**HIOW**)

Frimley Health & Care

Surrey Heartlands

Sussex Health & Care

Kent & Medway ICS

<https://www.england.nhs.uk/system-and-organisational-oversight/system-directory/south-east-region/>



Integrated Care Systems (ICSs)

Each ICS will deliver its aims differently, influenced by many things including leadership, partnerships and partnership working, its population and local pressures on health and care. Each ICS has developed a local strategy and plan with its ICP using evidence (data, information, local expertise and input etc) from local NHS Providers, Healthwatch, partners (including VCSE, Universities etc) and information from local people. There might also be an ICS plan for Children & Young People (CYP) developed with input from a formal CYP Partnership Board.

To plan and deliver the strategic aims each ICS is divided into smaller more manageable working areas - the ICS is divided into smaller Places and each Place divided into Neighbourhoods (see below) allowing the right delivery approach and aims for that the local population.

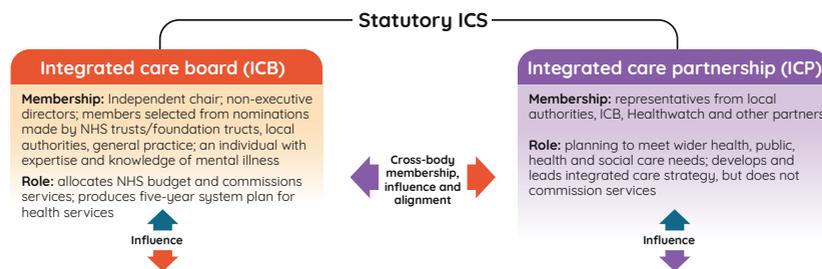
The purpose of ICSs is to bring partner organisations together to tackle complex challenges.

The Kings Fund Video - [How the NHS in England works and how it is changing](#) explains the division of an ICS into Place and Neighbourhood areas.

TheKingsFund

Integrated care systems (ICSs)

Key planning and partnership bodies from July 2022



Geographical footprint

System
Usually covers a population of 1-2 million

Place
Usually covers a population of 250-500,000

Neighbourhood
Usually covers a population of 30-50,000

Partnership and delivery structures	
Name	Participating organisations
Provider collaboratives	NHS trusts (including acute, specialist and mental health) and as appropriate voluntary, community and social enterprise (VCSE) organisations and the independent sector; can also operate at place level
Health and wellbeing boards	ICS, Healthwatch, local authorities, and wider membership as appropriate; can also operate at system level
Place-based partnerships	Can include ICB members, local authorities, VCSE organisations, NHS trusts (including acute, mental health and community services), Healthwatch and primary care
Primary care networks	General practice, community pharmacy, dentistry, opticians

Integrated Care Partnerships/Boards (ICP/ICB)

Within each ICS there are statutory ICPs who work in partnership with ICB.

The formal partnership and partnership working at ICP/ICB level is key towards an ICS meet its strategic aims, the NHS Long Term Plan and delivery to the local population.

Integrated Care Partnerships ICP will be made up of:

- **ICB members**
- relevant **local government members** (most likely Health & Wellbeing Board chairs)
- **ICS Place** leader executives
- **Clinical** leaders
- **Healthwatch** representatives
- representatives from **VCSEs** and possibly **other** partners.

Membership of the ICP should be transparent and easily available. You should be able to see individuals experience, skills, connections, and conflicts of interest.

Meeting agendas, how to submit questions and observe upcoming meetings with links should be available on ICB websites. ICBs also have YouTube channels to communicate their activities and messages.

Partnership, Collaboration and Co-production

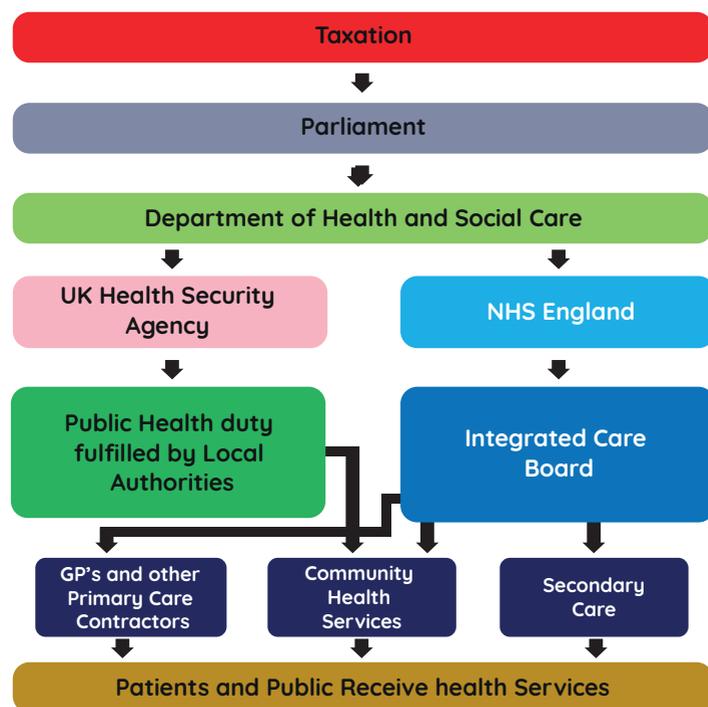
There is now a statutory duty on Partnership, Collaboration and Co-production.

The NHS has always worked well in co-production on an individual patient level through [Shared Decision Making](#) or discrete patient groups. Co-production on a larger scale with the ICS is a new way of working. New NHS England guidelines help ICS's understand partnership and collaborative working and the duty to work in partnership is clearly defined - [Building Strong integrated care systems everywhere](#) and [Statutory Guidance to support working with people and communities](#).

How the Money Flows in the New NHS System

- simplified.

The ICB is now the commissioner for most health services in your area delivering services via clinicians and practitioners e.g. GPs in Surgeries, Dentists, Opticians, Pharmacies, Hospital workers, Physiotherapists, Community Nurses, Health Visitors, Clinical Psychologists etc.



Taxes go to the government which decides the **Dept of Health & Social Care** (DHSC) budget (key decision makers are Secretary of State for Health & Social Care and Chancellor of the Exchequer). The largest proportion of DHSC budget flows to **NHS England** which in turn funds the 42 newly formed **ICBs** via their statutory **ICB**.

ICBs commission **health services** (Community Health Services, GP and other Primary Care)

in a local area for **Patients & Public**. Each ICB must ensure **system financial balance**.

The DHSC also gives a budget to the **UK Health Security Agency** (UK HAS) which is concerned with prevention and protection against biological, chemical, nuclear and other health threats. UK HAS gives budgets to local authorities who have a duty to fulfil public health duties and in turn commission **Community Health Services** for patients and public.

What are the Different Types of Health Organisations?

Health services are delivered by organisations known as NHS Providers or NHS Primary Care Providers.

Currently there are 215 NHS Providers.

These are the large organisations where clinicians deliver services to patients. NHS Providers are organised into discrete Trusts who usually deliver one focus of clinical care. NHS Foundation Trusts are hospitals or groups of hospitals or other organisations providing general, specialist, mental health, community or ambulance services to the local population.

They include:

Acute Provider

This is probably what most people think of when they think of the NHS - large hospital settings. Acute Providers might look after one or several hospitals. They provide diagnostics, surgery, inpatient care, Accident & Emergency, outpatient services such as Child Development Centres etc.

Community Provider

Delivers patient care in community settings (people's homes, schools, community buildings, or smaller community hospitals). Community providers keep patients with long term conditions well, away from unnecessary hospital admission or well at home recovering from hospital. This includes many services for SEND children such as Therapy Services, Health Visitors, Specialist Health Visitors, School & Specialist School Nurses, Community Nurses, Allied Health Professionals.

Mental Health Provider

Provides targeted and specialist mental health therapies (Child & Adolescent MH Services, Adult MH Services), inpatient MH hospital and specialist services for people with SEND (behaviour support or specialist therapies)

Primary Care Provider

The people you go to first when you need everyday care, keep you out of hospital or treat conditions that does not need hospital care (GP Practices, Community Pharmacy, Optometrist, Dentist). Primary care providers will have NHS contracts and targets but will 'feel' different to each other. The ICB now works more closely with all Primary Care Providers and now have more influence on GP Surgeries, NHS Dentists and NHS Ophthalmologists.

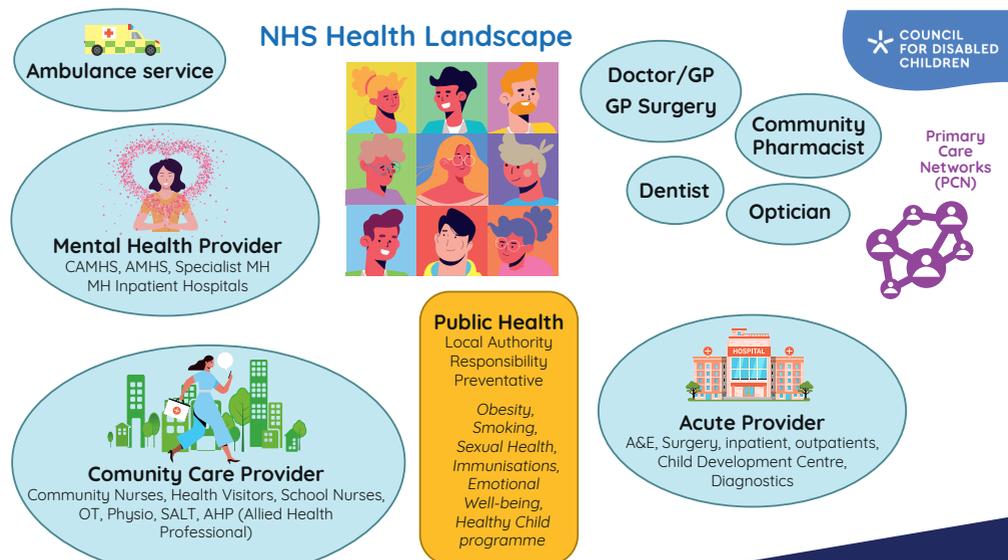
Ambulance Provider

Provides emergency care to patients, paramedics, technicians, and transport patients to Acute settings for further care. There are 10 Ambulance Providers across England each covering a large area.

- Some providers may provide both acute and community care.

Primary Care Networks (PCN)

Are usually led by GP practices working with each other and with community, mental health, social care, pharmacy, hospital or voluntary services in their local areas. PCNs enable greater provision of integrated supportive health and care services for people close to their home. Economies of scale mean that roles such as social prescribing can evolve to meet needs in an area – these could be very important roles for SEND families as they develop with time.



NHS Services for all Children Including those with SEND

You should expect to find the same core NHS across the whole country e.g. there will be GP Surgeries, Child Development Centres, School Nurses, Health Visitors, Continence Teams, Wheelchair services, Orthotic services, CAMHS and Neurodevelopment assessment services available in your area. Forums should pay particular attention to:

Healthy Child Programme

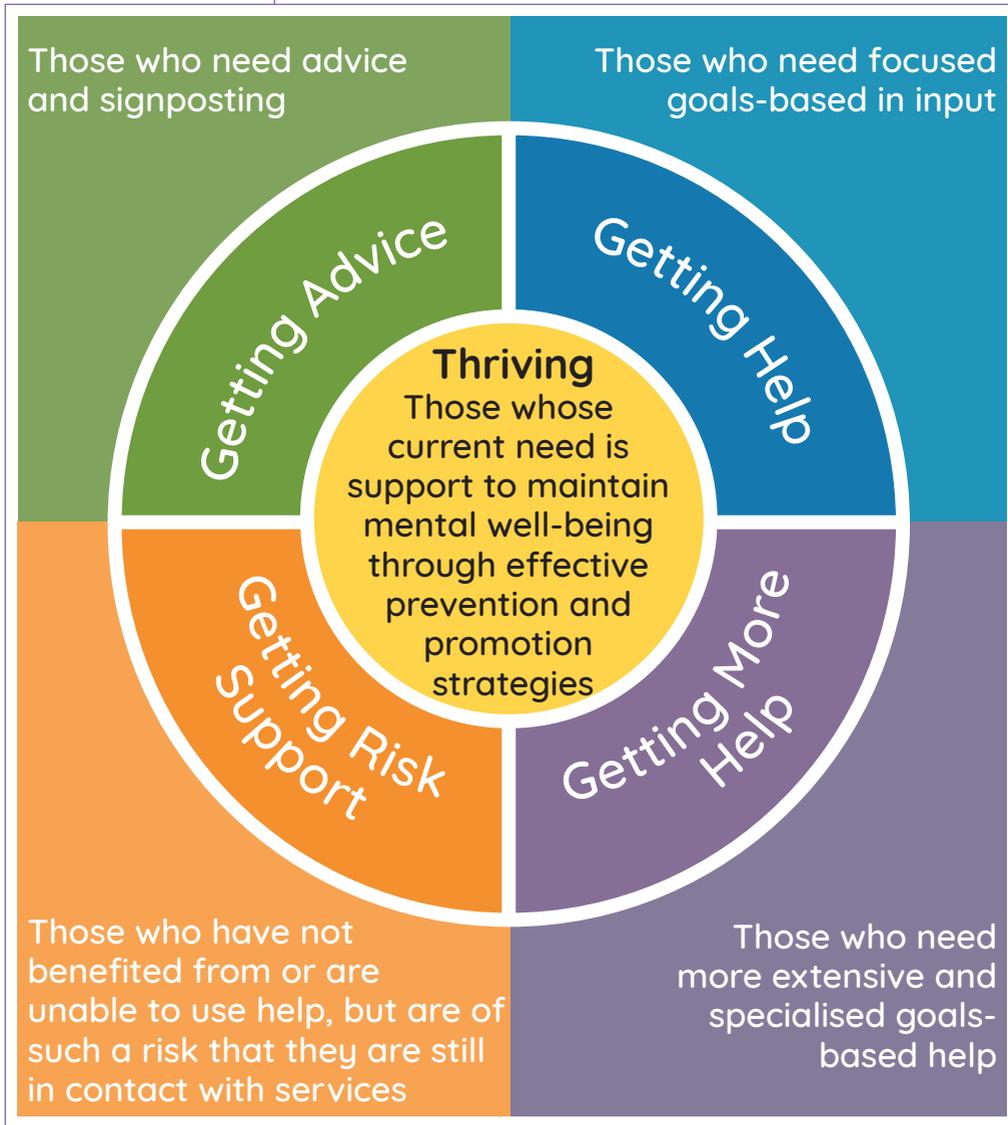
[Health Child Programme](#) is a preventative public health programme and supports families and children preconception to 19, or to 25 if there is entitlement. Public health is about reducing the causes of ill-health and improving people's health and wellbeing e.g. taking action to promote clean air, water and food are public health duties. Also, reducing obesity, helping people stop smoking, providing sexual health services, reducing teenage pregnancies, promoting good oral and dental health, promoting good emotional wellbeing and good mental health, and delivering a strong immunisation programme.

This is a huge piece of work – pay attention to the HCP in your area and ensure it meets the needs of children with SEND. It includes School Nurse and Health Visitor services and also emotional wellbeing and mental health services.

Children's Mental Health & Emotional Wellbeing services

The [THRIVE](#) framework is used to plan, commission and deliver emotional wellbeing and mental health services in an area. Child & Adolescent Mental Health Services are delivered by a wide range of agencies (such as schools, charities and local authorities) as well as the NHS, so CAMHS are much wider than the NHS. There will be a wide universal offer to support children's emotional wellbeing and mental health and support their family which includes School Nurses and GPs. Where there is a more significant need (such as seeking diagnosis, specialist treatment or medication) this is supported by specialist NHS CAMHS services.

Children's Mental Health & Emotional Wellbeing services - the Thrive Framework



Levels of Care for Children – Primary, Secondary (Targeted) & Tertiary (Specialist) NHS Services

The NHS is organised into levels of care from universal to specialist care. Services are accessed through evidence-based clinical need, with referrals being made by relevant (often primary care) clinicians or in some areas multi agency teams of expert practitioners. The levels of care are:



NHS works on evidence-based referrals

Primary Universal → Secondary → Tertiary

GP
Health Visitor
Pharmacist
Dentist
NHS 11
A & E
Minor treatment unit
Urgent treatment unit
School nurse

Community Paediatric
Speech and Language Therapy
Physiotherapy
Occupational Therapy
Community Nurses
CAMHS (Child & Adolescent Mental Health Service)
Special School Nurse

**Highly specialised
Healthcare services**

Specialist diagnostic service
Acute clinical service
Specialist treatment centre

Commissioning -

Primary care is now commissioned by the ICB and School Nursing is commissioned by the Local Authority (via the national Healthy Child Programme) delivered by clinicians working for a local NHS Provider.

Primary/Universal Services - anyone can access primary or universal services such as the GP or A&E (Accident & Emergency), phone NHS 111 or have access to their school nurse.

Key primary care roles:

Health visitors

Provide health education and health promotion advice. They can also provide supportive care to families with a 0-5-year-old.

School nurse

Every school will have a named school nurse. They provide health promotion and education to school aged children including children with SEND. School nurses can support children directly and parents can also talk to them.

CHATHealth

Is an award-winning texting and support, advice and listening service for 11-19, available in most areas.

Duty of care

There is a duty of care for children not at school e.g. those children educated other than at school (EOTAS) or home educated.

Secondary Services - Secondary health services are usually commissioned by the ICB. There are a few exceptions commissioned by NHS England. **The largest cohort of users of children's secondary health services are children with SEND.**

These are targeted or more specialist services which require a referral e.g. to see a Community Paediatrician or referral for an autism assessment. Sometimes other professional agencies such schools may also be able to refer.

Key secondary care roles:

Occupational therapists (OT)

Work with children using play and other activities to maximise their abilities in all aspects of daily living, including education. They will assess for any equipment required such as wheelchairs, bathing aids and adaptations to a child's environment. All certified OTs will be registered with the Royal College of Occupational Therapists. There are also OTs who work for the local authority, usually in social care for housing adaptations and equipment.

Physiotherapists (Physio):

Help and support difficulties with mobility movement or breathing, caused by illness or surgery. They will assess needs and abilities and set achievable goals and for a physical management programme. All certified physiotherapists are registered with the Health and Care Professions Council (HCPC).

Speech And Language Therapist (SALT)

Assess communication ability and advise on support. Speech & Language therapy is delivered as universal, targeted or a specialist service. Speech and language therapy service also have a specialist feeding team to support and advise on feeding and eating. The Royal College of Speech & Language Therapists is the professional body for SALTs.



Other Allied Health Professionals (AHPs)

In addition, there are other Allied Health Professionals (AHPs): Dietitian, Podiatrist, Paramedic, Radiographer, Orthoptist, Orthotists/Prosthetists, Drama Therapist, Play Therapist, Music Therapist.

Specialist Health Visitors

Support families with very young children with an identified condition or disability / SEND.

Special School Nurses

Special School Nurses are linked and often based at Special Schools and help with medication, nursing needs and support training of school staff. They are usually part of the Children Community Nursing teams, but do not exist in all areas and this can give fewer choices to families with medically complex children.

Child Adolescent and Mental Health Services (CAMHS)

Is the NHS services that assess and treat young people with emotional, behavioural or mental health difficulties. CAMHS support covers depression, problems with food and eating, self-harm, abuse, violence or anger, bipolar disorder, schizophrenia and anxiety, among other difficulties. Most CAMHS are secondary care services and include multidisciplinary teams comprising psychiatrists, community psychiatric nurses, psychotherapists and clinical psychologists, sometimes social workers and other types of therapists such as speech and language.

Learning Disability Nurses

Provide specialist healthcare and support to people with a learning disability (LD), as well as their families and staff teams. There should be LD nurses in most big hospitals, possibly assigned as a children's or adults LD nurse.

Community Learning Disability Nurses

Work in a Health Facilitation team, which help people with LD access health services. Patients are usually over 18 but this team can support young people from 14 with their Annual Health Checks for people with LD.

Community LD Team (CLDT)

A wider team of practitioners which provide assessment, care management, care coordination, therapeutic intervention (ie. behaviour or communication support) and health professional training and support for people with LD over 18. Usually delivered by mental health trusts.

Also includes audiology, continence nursing teams, wheelchair services and children's community nurses.

Tertiary - Secondary health services are usually commissioned by the ICB. There are a these are highly specialist services or settings requiring a referral from primary or secondary care. It may include specialist diagnostic services (e.g. genetics services, acute clinical services) or specialist emergency services (e.g. paediatric surgery, children's cancer services or specialist, inpatient Mental Health assessment & treatment units). Tertiary care includes specialist treatment centres for children and young people with low incidence, high-cost conditions.

Key tertiary care roles commissioned by NHS England:

Specialised CAMHS

These services are for more complex mental health problems and include specialised multi-disciplinary services and day units, highly specialised out-patient teams and in-patient units. They are usually accessed by referral from secondary CAMHS.

Specialised Centres of Clinical Excellence

Such as Great Ormond Street Hospital.



Key NHS Workstreams to be aware of

NHS addressing and reducing Health Inequalities

Health inequalities

[Health inequalities](#) are about differences in the status of people's health driven by the differences in the care that people receive and the opportunities to lead healthy lives. Health inequalities can therefore involve differences in:

- health status e.g. life expectancy
- access to care e.g. availability of given services
- quality and experience of care e.g. levels of patient satisfaction
- behavioural risks to health e.g. smoking rates
- wider determinants of health e.g. quality of housing

Core20plus5 and CYP Core20plus5

[Core20plus5](#) and [CYP Core20plus5](#) is the NHS targeted approach to reducing health inequalities in five clinical conditions (Asthma, Diabetes, Epilepsy, Dental Health and Mental Health) and in the most deprived 20% of a population. There are very clear SMART outcomes to work towards

NHS England Learning disabilities and/or autism programme

NHS England [Learning disabilities and/or autism programme](#) is about improving health and care services so that more people with a LD and/or autism can live in the community with the right support.

This is a huge programme with a focus on behaviour that challenges and a risk of hospital admission (Transforming Care) and a focus on the SEND Agenda.

This all-age NHS England programme supports the entire NHS workforce. It is about helping the NHS to understand how to fulfil duties set in law (i.e. [Reasonable Adjustments from the Equality Act 2010](#), and [NHS RightCare](#)), develops best practise ([Always Events](#) to co production with families and patients) and actively reducing health inequalities



HEALTH FOR PEOPLE WITH LEARNING DISABILITIES AND AUTISM
(TRANSFORMING CARE AGENDA)

- ### Improving health
- [Reasonable adjustments](#)
 - [NHS RightCare](#)
 - [Flu](#)
 - [Personal health budgets](#)
 - [Mortality review \(LeDeR\)](#)
 - [Summary care records](#)
 - [Patient Online](#)
 - [Always Events](#)
 - [NHS quality checking](#)
 - [Annual health checks](#)
 - [Stopping over medication of people with a learning, disability, autism or both \(STOMP\)](#)
 - [Supporting Treatment and Appropriate Medication in paediatrics \(STAMP\)](#)

through proactive processes such as the LD Annual Health Check, digital flagging through use of Summary Care Records and NHS App) and sharing real data (mortality review from LeDeR monitors avoidable deaths and seeks to address this).

Work includes:

Annual Health checks

[Annual Health](#) checks for ALL autistic people from 2030.

Oliver McGowen Mandatory Training (OMMT)

[OMMT](#) for the whole NHS workforce to understand autism and/or learning disabilities better.

Transforming Care

To support people with autism and/or LD who display behaviour that challenges live in the community and reduce unnecessary admission to inpatient units. The Winterbourne View scandal resulted in the [Transforming Care](#) Agenda and the NHS developed a plan to address this ([Building the Right Support](#)).

STOMP and STAMP

[STOMP](#) and [STAMP](#) which are around appropriate medication treatment for people with LD and/or autism. The [Dynamic Support Registers and the CETR/CTRs process](#) developed from this work.

Children with SEND

The [Children with SEND workstream](#) brings together DfE, DHSC, local authority, NHS England team and others to support the NHS workforce work in line with The Children & Families Act 2014 and produce guidance and best working practise. The Designated Clinical Officer (DCO) and Designated Medical Officer (DMO) roles evolved from this work and now Designated Social Care Officers (DSCO) should exist in all areas. Workstreams include:

Workstreams include:

NATP - National Autism Training Programme

Anna Freud and AT-Autism are delivering [NATP](#) training for NHS England. The training is co-designed, co-produced and co-delivered with autistic people and promotes an experience-sensitive, trauma-informed approach.

Childrens NHS Continuing Care (CHC)

For children up to 18 with complex medical needs [CHC](#) is now managed local by your ICB. There will be continual clinical reassessments. Eligibility criteria for adults continuing care is different so children so those with CHC may not be eligible for adults CHC.

Personal Health Budgets

A [Personal Health Budget](#) is NHS money allocated to support health and wellbeing needs and allows individuals to manage healthcare and support such as treatments, equipment, wheelchairs and personal care, in a way that suits them. It works in a similar way to personal budgets and direct payments, for social care needs.

Personalised Care

[Personalised Care](#) is one of the five major practical changes to the NHS set out in the Long-Term Plan. Personalisation means more choice and control for patients and especially for patients with low-incidence high costs needs.

Transition from children to adults' services

Transition should be a staged, planned process with everyone working together and not an event that happens at 18 years old.

There are [NICE guidelines](#) to support best practise to ensure smooth transition from children to adult services e.g. care from CAMHS is seamlessly delivered by Adult Mental Health Services (AMHS) children should not be discharged from CAMHS and then re-referred to AMHS.

Transition from children to adults' services - NICE guidelines

Transition from some families can be complex and stressful as many different agencies need to be involved and work together, where there are fewer adult clinicians compared to paediatric clinicians or they work over much larger areas.

Covid pandemic and Children's health services

The Covid pandemic was a national emergency. To keep the NHS functioning the NHS had to reorganise and deliver care differently. Most of the children's services paused throughout the pandemic with the majority of staff redeployed to work in critical areas of the NHS.

Significantly - the pandemic exposed health inequalities and inequities that already existed and exacerbated them. Children's services are now back operating, but the impact on missed therapies, assessments and diagnosis is being seen with huge waiting lists and waiting times for services, lost interventions for children who are now in adults' services.

Some Ideas to Help Partnership Working

CQC (Care Quality Commission) & OFSTED SEND Inspections. Work together with your ICB to measure impact and use this data at SEND/other board level to assure, monitor and improve SEND services.

Do all ICS partners understand what PCFs are, what you do, how you can help and be a partner? Consider positively and proactively raising your profile as allies as individual Forums in an ICS or across the region using NHS England SEND and Regional Advisors.

Engage with your membership around health issues and collect impartial feedback, good and bad, with a view to helping the ICS.

Give your membership information about the local NHS health system and help them develop skills (around participation, giving feedback, raising concerns & complaining, information on things that that will help their family such a registering as Carer with GP)

Have co-listening type events with health services.

Share knowledge and information. Encourage uptake of Annual Health Checks, Data flagging, Transforming Care, DSR & CETRs, Flu Jabs, Reasonable Adjustments, Mental Capacity Act, Challenging Behaviour support, networks and strategies, Person-centred tools such as One-page Profiles, Hospital Passports and people that can help, LD nurses, Health facilitation teams, Autism support services etc.

Support digital inclusion. Help parents use NHS App and understand linking profiles through Summary Care Records. Get digital savvy and help parents. Reduce health inequality here. There is a huge NHS initiative to digitally join up information from providers and help better inter-working.

Understand your area Join Strategic Needs Assessment (JSNA) and understand the children & young people's issues raised at Health & Wellbeing Board, Safeguarding Board, CYP Board and other strategic boards to understand system issues.

Understand SEND data and how it fits into the whole CYP health data.

Understand the commissioning cycle and the points where you can make a difference.

How could you help your parent carers more to get the best health outcomes for their child and family?

Understand the role of regulators and identity how they can help you; CQC, Healthwatch, Health Ombudsman, Patient Advice & Liaison Service (PALS) in each NHS Provider. Individual Governors and the Council of Governors in Foundation Trusts, Provider Boards, Patient Participation Groups in GP Surgeries and other advocacy partners.

Understand all CYP services delivered across your area and how they work, in particular the Health Child Programme and emotional wellbeing and mental health services commissioning.

Look at where services are differentiated to support SEND children and reduce health inequalities. What works well, what could be improved?

Look at specialised services e.g. epilepsy nurses, diabetes, wheelchair services and dentistry. Transition from children to adult services.

Find out how children not in school's universal health needs are delivered/being met. How is CHATHealth working in your area? how is this being communicated to children with SEND?

Other Sources of Guidance, Information & Knowledge

Council for Disabled Children



A joined up Education, Health and Social Care focus 0-25. Youth Voice. Free E-learning including Personal Health Budgets, Continuing Care etc. E-learning courses include Introduction to Mental Health; Introduction to Social Care; Information, advice and Support; Holistic Outcomes in EHCPs, Delivering quality Annual reviews, Focus on Health Advice, CETRS & DSR.

<https://councilfordisabledchildren.org.uk>

Disabled Children Legal Handbook



<https://councilfordisabledchildren.org.uk/resources/all-resources/filter/inclusion-send/disabled-children-legal-handbook-3rd-edition>

Cerebra



Factsheets, guidebooks, support advice, grants, special equipment, renowned sleep service.

<https://cerebra.org.uk>

Contact



For families with disabled children.

<https://contact.org.uk>

NDTi



Support and train Experts by Experience involved in CETRs. Evaluate many programmes.

<https://www.ndti.org.uk>

Bringing Us Together



Family led campaigning and support group produce helpful guides including Survival Guides for CETRs etc.

<https://bringingustogether.org.uk>

Challenging Behaviour Foundation



Campaign and work with NHS and LAs to support families with children with learning disability and behaviour that challenges. Lots of information on medication/ STOMP/ STAMP/positive behaviour approaches etc.

<https://www.challengingbehaviour.org.uk/understanding-challenging-behaviour/what-is-challenging-behaviour/>

Autistica



Work to support evidence-based approaches that help autistic people have happy, healthy, and long lives.

<https://www.autistica.org.uk>

Well at School



Supporting children with medical and mental health needs at school - information, strategies, resources, podcast etc.

<https://www.wellatschool.org>

Together for Short Lives



Charity for families with seriously ill children. Financial advice, emotional and practical support.

<https://www.togetherforshortlives.org.uk>

Well Child



Charity for seriously ill children helping them thrive at home. Sponsor Well Child nurses. Also lists places for funding, support etc.

<https://www.wellchild.org.uk>

NICE



National Institute for Health & Care Excellence - produces guidance and standards to help health and care professionals and organisation.

<https://www.nice.org.uk>

Anna Freud Centre



Support and evidence-based training for professionals for children mental health and emotional wellbeing issues.

<https://www.annafreud.org>

Health Foundation



Help inform policy, research, and analysis in health & care.

<https://www.health.org.uk>

Kings Fund

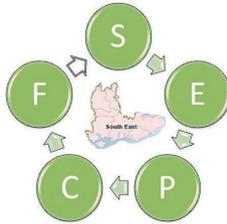


charity and think tank that explains and helps the health & care system. Great blogs and explainers. Useful videos.

<https://www.kingsfund.org.uk>

A GUIDE TO SUPPORT PARENT CARER
FORUMS IN THE SOUTH EAST

Demystifying the **NHS**



This booklet was produced by the South East Parent Carers Forums through funding from NHS England-SE.

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