

Preventing Inappropriate Admissions to mental health hospitals for children and young people with Special Educational Needs and/or Disabilities (SEND)

Information for Parent Carers

Supporting children and young people with a learning disability, autism or both who have a mental health condition, and their families.



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This information has been produced by parents from Parent Carer Forums across the Eastern Region. We hope it will be useful to all parent carers of children or young people with SEND who have a mental health condition, but it is specifically written for parent carers of those who also have a learning disability, autism or both. Its purpose is to provide you with background information on what is happening in the NHS at the moment, the NHS Long-Term Plan and what this might mean for your family, and the services available locally to support your child or young person today. Hereafter children and young people with a learning disability, autism or both will be referred to as 'our children and young people'.

In Education and Social Care the term 'young people' refers to those aged 17 to 25 years. In some NHS areas 'young people' are those aged 17 and 18 years, with 19 to 25 year olds being referred to as 'adults'.

If you need help for a mental health crisis or emergency, you should get immediate expert advice and assessment. Information is available from the NHS website [HERE](#). NHS 111 Option 2.

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NHS England and NHS Improvement: What the NHS Long Term Plan says

“Children, young people and adults with a learning disability, autism or both, with the most complex needs, have the same rights to live fulfilling lives”.
(Quote NHS Long Term Plan 3.34)

Our children and young people have the right to the same opportunities as anyone else to live satisfying and valued lives, and to be treated with the same dignity and respect. This includes those whose behaviour can lead to contact with the criminal justice system or those with another mental health condition including difficulties relating to eating. They should have a home with their family or within their community, be able to develop and maintain relationships and get the support they need to live a healthy, safe and fulfilling life.

The aim: ‘Homes not Hospitals’

The NHS Long Term Plan says that “no more than 12 to 15 children and young people with a learning disability, autism or both per million, will be cared for in an inpatient facility by 2023/24”.

The NHS Long Term Plan has also made commitments to keyworkers for children and young people with the most complex needs, initially those in a mental health inpatient setting; to developing community services and to reducing overmedication of our children and young people and to developing dynamic support registers.

The Mental Health Act says children and young people should have the **least** possible separation from their family, friends and community, or breaks in education. There will always be cases where admission to a mental health inpatient facility is the optimal course of treatment for a mental health need. This information aims to prevent **inappropriate** admissions which occur because of a lack of understanding of the importance of having local services to meet the needs of the children and young people in local areas.

Delivering through Local Services

Local services work best when they are jointly commissioned community care services. This covers services set up by NHS Clinical Commissioning Groups (CCGs) **and** the Social Care and Education departments of Local Authorities **working together**. This was initially achieved through Transforming Care Partnerships (TCPs). TCPs were made up of clinical commissioning groups (CCGs), NHS England’s specialised commissioners and local authorities. Since 2016 TCPs have become Sustainability and Transformation Partnerships (STPs) and in some areas STPs have evolved to become ‘integrated care systems’ (ICSs), a new form of even closer collaboration between the NHS and local councils. The NHS Long Term Plan set out the aim that every part of England will be covered by an integrated care system, ICS, by 2021, replacing STPs but building on their good work to date. They will continue to work with people with a learning disability, autism or both and their families and carers to agree and deliver local plans.

Each local area is different: local populations have different needs, and their range of providers have different strengths and weaknesses, so services will not look the same everywhere. Each local area has been drawing up its own model for how services should look in future, based on a National Service Model called 'Building the Right Support' and established best practice.

Work is underway in all areas but some areas are further ahead than others. Parent Carer Forums across the East of England are feeding back the lived experiences of families in their area to highlight gaps in services and to help improve service provision and improve the experiences of children, young people and their families. If you want to find out more about your local Parent Carer Forum, you can do so [HERE](#).

Tier based Local Services

Support for mental health problems for all children and young people is Tier based

Tier 1 – Universal mental health services provided by professionals who do not specialise in mental health e.g. Teachers.

Tier 2 – Mental health services provided by practitioners who specialise in mental health e.g. counsellors.

Tier 3 – Specialist Child and Young People's Mental Health Services, CYPMHs / CAMHs

Tier 4 – Inpatient / Highly specialised mental health services.

Page 7 of this document gives more information on the support available locally, including names and contact details, so you can get help and support for your child or young person.

Dynamic Support Registers of Children / Young People who need extra support

Local health and social care services need to know who is most at risk of inappropriate responses by services. CCGs must now have a register of children and young people who have a Learning Disability, Autism or both and are at risk of going into, or are in, inpatient mental health settings. This is part of Building the Right Support. The register, called the **Dynamic Support Register (DSR)** should help children, young people and adults get the support they need before their problems get too serious and certainly before they need to go to hospital.

Your child, young person or adult should be on this register if they:

- Are currently in a hospital setting;
- Are referred for or accessing specialised services for challenging behaviour (e.g. intensive support services, specialist short breaks, special schools, residential care and supported living);
- Are subject to the provisions of the Mental Health Act or subject to Deprivation of Liberty safeguards;
- Have had a previous hospital stay (for example, within the last 5 years);

- Are / were involved with the youth or criminal justice system (for example, within the last 12 months);
- are children in 52-week educational placements;
- are in receipt of NHS Continuing Health care (CHC) funding;
- are in receipt of services from youth offending teams (YOT).

Page 7 of this document gives details of your local Dynamic Support Register.

Personalised Care and Support for Children and Young People

The NHS, together with Local Authorities are moving towards the aim of having one person, a Keyworker, as the central point of contact for a child or young person with a learning disability, autism or both who has a mental health condition, and their family members and carers, and the services involved in their care. At the moment in the East of England, the Keyworkers are part of an 18-month pilot project running in just two areas - Bedfordshire, Luton & Milton Keynes and Hertfordshire. Keyworkers in these pilot areas will only be for a small number of children and young people who:

- Have been diagnosed with a learning disability and/ or autism;
- Are under 18 years old or have yet to move to adult services;
- Are currently an inpatient in a mental health hospital, or are considered to be at risk of a hospital admission.

If successful the pilot schemes will be offered to many more families. The aim is that Keyworkers will work across all health, education and social care systems and will be different to a care coordinator. Keyworkers will work alongside any existing workers / professionals, as an addition to not a replacement for them. They are there to support you and your family and will take the time to learn what is important to you and what works best for you. Keyworkers will keep you and your family at the centre of decision making, so decisions will be made with you, not for you.

The belief is that having someone support children, young people and their families might help avoid inappropriate mental health hospital admissions in the future.

CETR – a Person Centred Plan for your child / young person

Children and young people up to the age of 18 who need extra support (see list on page 4) have the right to a **Care, Education, Treatment review (CETR)**. A CETR should start when a hospital admission is being considered. You also have the right to ask for a CETR for your child or young person at any time if you have concerns about a placement breakdown, if there is a crisis or if there is a risk of inpatient admission.

If your young person is over 18, this will be called a Care Treatment Review (CTR).

CETRs are for children and young people who have learning disabilities and/or autism and who **have been**, or may **about to be** admitted to a specialist mental health hospital (Tier 3 or Tier 4). The CETR makes sure that local services (social care, Special Educational Needs

(SEN) Team and school or college) are involved so all issues can be addressed and solutions found.

There are three people on each CETR Panel: An expert by experience (a person with learning disabilities and or autism OR a family carer with experience of services), a clinical expert and the commissioner (who pays for the person's care). The commissioner is the chairperson and must make sure the actions on CETR are delivered. All the people on the panel are independent and not involved in the child or young person's day to day care. The panel should interview the care team for example the community psychiatrist, social worker and community nurse, so their views are heard by the panel.

The child's parent or the young person must give consent to hold a CETR and be able to invite family or others to support them during the panel.

Remember the Children and Families Act says that local authorities and services must consider the views, wishes and feelings of children, young people and their parents when supporting children and young people with SEND up to the age of 25. It also says the child and his or her parent, or the young person, should have the support they need to take part in decisions. The Mental Health Act says young people should have the chance to be involved in their own care and treatment and Parents and carers have a central role in decisions about their child.

The actions and recommendations are agreed during the panel, but the chairperson has two weeks to write the CETR or CTR. It must have clear actions and a named person who will do each action within a certain time. It is up to the chairperson to make sure these actions happen; if they do not happen the Commissioner must explain why. The panel will challenge poor ways of working and support a move towards community-based care, but its recommendations are not binding.

A CETR does not decide whether to admit or discharge someone from hospital – this is for the clinician to decide – but a CETR can make recommendations about other options in non-urgent cases.

The Local Offer in your area

The Local Offer in your area gives children and young people with special educational needs or disabilities and their families information about what support services the local authority think will be available in their local area. By law, every local authority is responsible for writing a Local Offer and making sure it is available for everyone to see. The easiest way to make it available is on the internet. A link to the Local Offer for Peterborough (City of) is found [HERE](#).

There will be many different types of services that children and young people may need, including support services in school and specialist health services. Every local Authority must talk with children and young people with Special Educational Needs and / or Disabilities, and their families to find out what sort of support and services they need.

LINKS, RESOURCES AND CONTACTS TO HELP YOU

If you need help for a mental health crisis or emergency, you should get immediate expert advice and assessment. Information is available from the NHS website [HERE](#). **Plus local crisis number as above**

The NHS Child and Young Person Mental Health Service, CYPMHS provides help and advice for parents and carers to deal with behavioural or other problems their child / young person is experiencing. It can be found [HERE](#).

Lots of general advice and support can be found online.

For more general advice, see the NHS [information on mental health and wellbeing](#), which includes advice about:

- [talking to children about feelings](#)
- [spotting signs of depression in children and teenagers](#)

YoungMinds

YoungMinds offers free confidential online and telephone support to anyone worried about the emotional and mental wellbeing of a child or young person up to the age of 25. You can call the free parents' helpline on 0808 802 5544 from 9.30am to 4pm, Monday to Friday or look at the website [HERE](#)

Royal College of Psychiatrists

You can also find out more by exploring [the Royal College of Psychiatrists' leaflets for parents and young people](#).

Local Voluntary Sector Services

There are many services to go to for help without having to ask for a referral, including crisis helplines that anyone can call. You can use the postcode finder to look up local services that provide mental health support for young people, including phone numbers and website details [HERE](#).

When to seek professional help

There's a difference between feeling a bit low from time to time and a serious emotional health problem. If your child is feeling unhappy and low for a prolonged period of time, or if you have any other serious concerns about your child or young person, it's time to seek more professional help.

Any professional working with children and young people should know what to do. You may find it helpful to speak to your GP, who may refer you a specialist children and young people's mental health service (CYPMHS). *This used to be called Children and Adolescent Mental Health Services (CAMHS).*

How do I get help from specialist CYPMHS?

Getting help from a specialist CYPMHS is different depending on where you live. Waiting times can vary too.

1. Most CYPMHS have their own [website](#) which will have information about access, referrals and more, including phone numbers, so you can get in touch directly for detailed advice.
2. Look at your local clinical commissioning group (CCG) website and search for children and young people's mental health. Use the postcode finder to find your local Clinical Commissioning Group (CCG) [HERE](#).
3. If you or your child is being supported by social services or the youth offending team, your case support worker will be able to refer your child for an appointment with someone in specialist CYPMHS.

General information about children and young people's mental health services, CYPMH can be found [HERE](#)

You can download the full version, an easy read version or a two page summary of the **NHS Long Term Plan**, or watch a brief video about the Long Term Plan [HERE](#)

The NHS Mental Health Implementation Plan 2019/20 – 2023/24 is found [HERE](#)

The full version of the NHS National Service Model '**Building the Right Support**' is found [HERE](#). An easy read version of 'Building the Right Support' is found [HERE](#).

Parents have written a **Family survival guide to a CETR**. It can be found [HERE](#)

The Children's Commissioner has written a 2020/21 report on mental health services which you can read [HERE](#).

Peterborough's Offer

Peterborough City Council Local Offer [website](#), lists services to support with mental health in Peterborough.

Peterborough's First [Response](#) (Mental Health Crisis) Call 111 option 2

Peterborough's Tier 2 offer

[Keep Your Head](#), Keep Your Head brings together reliable information on mental health and wellbeing for children, young people and adults across Cambridgeshire & Peterborough.

[Kooth](#), Is a free online service to support young peoples mental health, the service offers online chat, discussion boards and information. They also provide one-to-one sessions.

[Center33](#), A service supporting young people up to the age of 25 with mental health, caring responsibilities, housing, sexual health and more.

Dynamic Support Register And CETRs

The Cambridgeshire and Peterborough CCG has a Dynamic Support Register, this contains information about young people that need more intensive support. Cases can move between the DSR and the Transforming care register. People on the Transforming care register will receive regular CETRs. For more information see a guide to CETRs [HERE](#)