Improving Health Care: learning disabilities and autism

A guide for schools, parents and health professionals to services available for children and young people with a learning disability and/or autism

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First published in 2020 by nasen

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ISBN: 978-1-911656-01-2

Registered Charity No. 1007023
Registered Company, limited by guarantee,
No. 2674379 (England and Wales)

A catalogue record of this publication is available from the British Library.

About this miniguide

Uptake of and access to appropriate health care for children and young people with learning disabilities* and autism, has been identified as an issue by the NHS. This has led to overuse of medication, in some cases, and others not receiving the treatment and care that they need.

This miniguide aims to:

- **Raise awareness amongst education professionals of the health provision and procedures available to children and young people with learning disabilities and autism,**
- **Inform education settings so they can support children and young people and their parents to access and engage with available health services and**
- **To raise the awareness of health professionals working with children and young people and their families regarding the support that should be available.**

Ultimately the aim is to promote more collaborative and joined up working between stakeholders of different backgrounds be they health or education professionals, parents or young people themselves. As well as improving the knowledge of school-based staff regarding health care, the guide will also help them to support parents, carers and young people, so that they know what is available to them and what to ask for.

To achieve these aims, the guide provides information about current initiatives in the NHS, Clinical Commissioning Groups, annual health checks, the dynamic risk register, Care, Education and Treatment Reviews and STOMP-STAMP.

Links to further information are provided at the rear of the guide; text in bold indicates those subjects for which links are available.

*learning disabilities is the term used by the health sector rather than learning difficulties or needs which is the preferred term in the education sector

Initiatives and Principles

The NHS Long Term Plan (LTP) – Learning Disability and Autism

The LTP (2019) sets out how the NHS will drive better quality care, address health inequalities and improve support for children and adults with autism, a learning disability or both. Commitments include:

- NHS staff to receive information and training on supporting people with a learning disability and autism.
- Tackling the causes of illness, disease and preventable deaths in children and adults with a learning disability and for autistic people, through work on reducing health inequalities, annual health checks and the **'Learning from deaths of people with a learning disability' programme** (LeDeR).
- Working with children and young people's services to improve access to and reduce waiting times for autism diagnosis for children.
- Introduction of a digital flag in 'summary care records', by 2023/24, to enable NHS staff to easily make adjustments for autistic people and people with a learning disability in a variety of health settings.
- All services funded by the NHS adopt the NHS **Learning Disability Improvement Standards**.
- Working with partners to have hearing, sight and dental checks for children and young people in special schools.

- By 2023/24 children and young people with the most complex needs will have a designated key worker.

Sustainability and Transformation Partnerships (STPs) and Integrated Care Systems (ICSs) should clearly set out how they will deliver the LTP commitments, including:

- Learning disability and autism physical health checks for at least 75% of people aged over 14 years;
- How proposals for people with learning disabilities and/or autism align with plans for mental health, special educational needs and disability (SEND), children and young people's services and health and justice and
- A local offer for autistic young people, people with a learning disability and their families.

Co-production with people and families

The LTP is committed to greater personalisation of care and giving people more control over their own health. A one-size-fits-all health and care system simply cannot meet the increasing complexity of people's needs and expectations. Personalised care is based on 'what matters' to people and their individual strengths and needs. The NHS Long Term Plan says personalised care will become business as usual across the health and care system and Universal Personalised Care confirms how this will be achieved (www.england.nhs.uk/personalisedcare/).

Systems are expected to involve people with lived experience and their families in checking the quality of care, support and treatment, and set out how they will ensure all local services make reasonable adjustments for people with learning disabilities, autism or both, when they need it.

Co-production with children and adults with a learning disability, autism or both and their families is important because:

- Insight from families reflects lived experiences, what works, and helps professionals to understand the whole person,
- It meets legal obligations e.g. Mental Health Act, Children and Families Act, Care Act, Mental Capacity Act, NHS Constitution,
- Not listening to families' feedback, concerns and complaints affects the quality of services (Ask Listen Do),
- Not working with families contributes to health inequalities and early death,
- The NHS Long Term Plan and the Transforming Care programme are built on a co-production model, and
- Person-centred care depends on it.

Transforming Care is all about improving health and care services so that more people can live in the community, with the right support, and close to home.

Ask, Listen Do

NHS England carried out a survey which nearly 1,300 people took part in. Some of the main results from this survey were:

- Nine out of ten people said that they had wanted to raise a concern or make a complaint at some time,
- Two out of three people said they sometimes or never knew how to do this and
- Seven out of ten people said that they did not feel that their complaint(s) had changed the way the organisation supports people.

As a result, with 12 partners including the Department for Education and Ofsted, NHS England is leading a programme of work called **Ask Listen Do** which aims to help children, young people and their families be empowered to have their voices heard as well as helping organisations (across education, health and social care) to have the right skills and systems to hear from people and to act on that to ensure good quality and safe care and support.

Based around the 4 themes of partnership, communication, processes and leadership and culture, organisations are asked to sign-up to the principles of more effective working **with** children, young people and their families in order to improve their outcomes.

Co-designed and co-produced resources for families, parents/carers, children and young people and organisations can be found at https://bit.ly/2tHfhuE

To support parents and carers to have more effective conversations in schools, Whole School SEND produced a useful leaflet of questions for parents to ask called 'A Guide to making conversations with schools count for all families': https://bit.ly/2ZeVdNQ

Clinical Commissioning Groups (CCGS)

CCGs are the commissioners of most of the hospital and community NHS services funded by NHS England.

To make contact with your local CCG visit: https://bit.ly/2hQF129 and find out more about member roles at https://bit.ly/2I872i6.

CCGs and Autism

CCGs, along with local authorities, should be aiming to improve the quality of care for children and young people with autism. CCGs and local authority social care and education commissioners should work together to commission person-centred care that is coordinated across all relevant organisations and partners in the **autism care pathway**.

Evidence suggests that a lack of autism awareness means that it can go unrecognised, or that necessary reasonable adjustments are not made, both of which impact on getting the right help and support.

CCGs, Education, Health and Care Plans (EHCP) and SEN Support

CCGs:

- Have a duty to inform local authorities about children (under compulsory school age) who in their opinion are diagnosed with or **may** have a special educational need or disability (Section 23 Children and Families Act 2014),
- Must secure the provision detailed in an EHC plan (Section 42(1) Children and Families Act 2014),
- Must have mechanisms in place to ensure practitioners and clinicians will support the integrated assessment process (Section 9.70 SEND Code of Practice, DfE January 2015),

- Must input into social care transition planning from child to adult services and
- Are required to consider the extension of **Personal Health Budgets** (PHBs); a personal health budget is an amount of money for supporting the healthcare and wellbeing of a child or young person. They are planned and agreed between individuals, parents/carers and the CCG. It is a way of spending healthcare funding to meet the needs of an individual.
- CCGs must continue to work with local authorities and schools on the implementation of integrated EHC plans and the offer of personal budgets.
- Must ensure that health care provision specified in an EHCP is made available to children and young people with Special Educational Needs (SENs) or disabilities.
- Commissioners, either CCG or NHS England are responsible for overseeing implementation and co-ordination of Care Education Treatment Reviews.

As identified by the Transforming Care initiative, if the right support is not available for children and young people in their local communities from health and other services, they may have to go into Mental Health settings (including Assessment and Treatment Units) which can be far away from home.

Read about Josh from Cornwall and how Transforming Care helped him to return home after spending three years in a specialist hospital in the West Midlands: https://bit.ly/2ZaWGbT.

Key points in making transforming care work

- Commitment from everyone
- Building strong relationships with all involved
- Strong multi-disciplinary team support
- Families are important parts of the team
- A good provider who understands a child, or young person's condition is necessary
- One-size does not fit all – different approaches for children and young people are required
- Listen to parents
- Person-centred planning is essential

Benefits of good transforming care

- Smoother transitions from assessment and treatment units for children and young people from specialist care back to home
- Helps children and young people to live a more ordinary life
- Reduction in medication use

Annual Health Checks

As part of the NHS Long Term Plan the introduction of a specific health check for people with autism will be piloted and if successful, will be rolled out more widely. Annual health checks are provided by GP's and are an important way to ensure health needs are understood and met. They are already required for those with a learning disability from the age of 14 and are a free service (not to be confused with NHS Health Checks).

How can a child, or young person access an Annual Health Check?

GP surgeries often invite children and young people who are on their learning disability registers. A learning disability register is a list of people with a learning disability who use the GP surgery, which helps doctors to make adjustments to the care they provide.

If a child or young person thinks they have a learning disability, they can request to be put on a learning disability register; they do not need to be diagnosed with a learning disability to be included on it.

A child, or young person does not have to be ill to have an annual health check and they should be encouraged to identify problems early before they become serious.

If a GP surgery will not provide an annual check, a child or young person (or parent/carer) should be directed to their local community learning disability team for advice.

What happens in an Annual Health Check?

During the health check, the GP or practice nurse will:

- Carry out a physical check-up, including height, weight, heart rate, blood pressure and take blood and urine samples.
- Talk to the child or young person about staying well and if they need any help with this.
- Ask about things that are more common with learning disabilities, such as epilepsy, constipation or problems with swallowing.
- Talk about any medicines the child or young person is taking.
- Check on other health problems such as asthma or diabetes, to see how they are going.
- Check to see if the child or young person has any other health appointments, such as physiotherapy or speech therapy.
- Ask if family and/or carers are getting the support they need.
- Help make sure that things go well when the child or young person moves to adult services at the age of 18.

The child or young person will also be asked for permission to share information with other services that provide their care. The GP or practice nurse will also provide health information, such as advice on healthy eating, exercise, contraception or stopping smoking. All aspects of the health check are voluntary.

Dyamic Risk Register

The Transforming Care programme recommends that local services should use a dynamic risk register to gather data on children and young people with a learning disability and/or autism.

The term 'dynamic register' is used to describe a process for risk stratification (the probability of someone succumbing to a particular disease or condition) of the local population of children and young people with a learning disability and/or autism who have mental health problems and/or present behaviour that challenges.

Commissioners within CCGs and local authorities are responsible for developing dynamic risk registers and commissioning activity in relation to it.

How will it help?

- Local services will be able to anticipate and meet the needs of children and young people with a learning disability and/or autism who display behaviour that challenges, or who are at risk of displaying behaviour that challenges.
- Local services will be able to plan appropriate, early interventions including preventative support.

- Governance arrangements will be made locally, including:
  - – responsibility for the register including updating
  - – the process for managing the register including reviewing and updating
  - – ensuring information sharing agreements are in place between parties
  - – identifying where the register is held

How schools may contribute to Dynamic Risk Registers

Within local areas there are already a range of statutory requirements for identifying children and young people with SEND. This may be helpful to local CCGs and Transforming Care programmes as they develop and ensure children and young people are included on their register.

The Ofsted and CQC SEND inspection framework assesses how well local areas identify children and young people with SEND in the local area.

Local intelligence

The range of local intelligence that CCG commissioners hold in relation to children and young people with learning disabilities and/or autism, that display behaviour that challenges varies considerably.

Improving this knowledge will lead to improved awareness of need and more responsive commissioning. This is important to ensure that children and young people with learning disabilities and/or autism, or both, are supported to stay well, have appropriate support to remain in the community and unnecessary admissions are avoided.

Summary Care records for health information is an important way to ensure that needs and reasonable adjustments are understood across all health and care settings including for GP surgeries, acute hospitals etc. Parents can elect for their child to be removed from the record.

Care, Education and Treatment Reviews

NHS England developed Care Education and Treatment Reviews (CETRs) to improve the care of children and young people with a learning disability and/or autism whose behaviour challenges others. Children and young people who need CETRs or may need them should be included on the Dynamic Risk Register.

A CETR will help to establish if a child or young person needs to be admitted to a specialist mental health/learning disability hospital (in the NHS or independent sector) or whether their care and treatment needs could be met effectively and safely in the community, through extra support or interventions.

CETRs will only be applicable to a minority of children and young people who are at risk of going into or are already in a mental health inpatient setting.

Factors that could place someone at risk of admission to hospital may include but are not limited to:

- Significant life events and/or change such as bereavement or abuse
- Unstable/untreated mental illness
- Pain or distress from physical health issues (both diagnosed and undiagnosed)
- Previous history of admission(s) to treatment units/hospitals

- Presenting significant behavioural challenges
- Excluded from school
- Being supported in an unstable environment or by a changing staff team
- Not being previously known to learning disability services
- Having no fixed address
- Being in contact with the Criminal Justice System
- Presenting ‘in crisis’ at Accident & Emergency Departments
- Having no family carers/advocates
- Having drug and alcohol addiction problems
- Having no effectively planned transition from child to adult learning disability services
- Having recently been discharged from long stay hospital beds
- Those in receipt of services from youth offending teams
- Those in receipt of Continuing Healthcare funding.

Principles that underpin Care, Education and Treatment Reviews

CETRs are based on a set of principles around the word **PERSONAL**:

1. Child and Young **P**erson-centred and family centred
2. **E**vidence based
3. **R**ights led
4. **S**eeing the whole person
5. **O**pen, independent and challenging
6. **N**othing about us without us
7. **A**ction focused
8. **L**iving life in the community

Who is involved?

CETRs are driven by the NHS but involvement of local authorities and education services in the CETR process and its outcomes, are necessary for improving care and treatment for children with learning disabilities and /or autism and their families.

CETRs that are held without the relevant professionals are unlikely to lead to the best outcomes for children and young people. Therefore, every consideration should be given as to how to ensure attendance.

How is a CETR triggered?

The CETR process is triggered at the point when a child, or young person is identified as being at risk of admission to an inpatient setting. The CETR can be requested at any point where there are concerns regarding suitability of a service, the treatment plan, the child or young person's safety and wellbeing.

Families can ask for a CETR if they need one or if one hasn't been offered. In addition, young people, advocates, clinical or community teams, local authorities and clinical commissioners can all request a CETR.

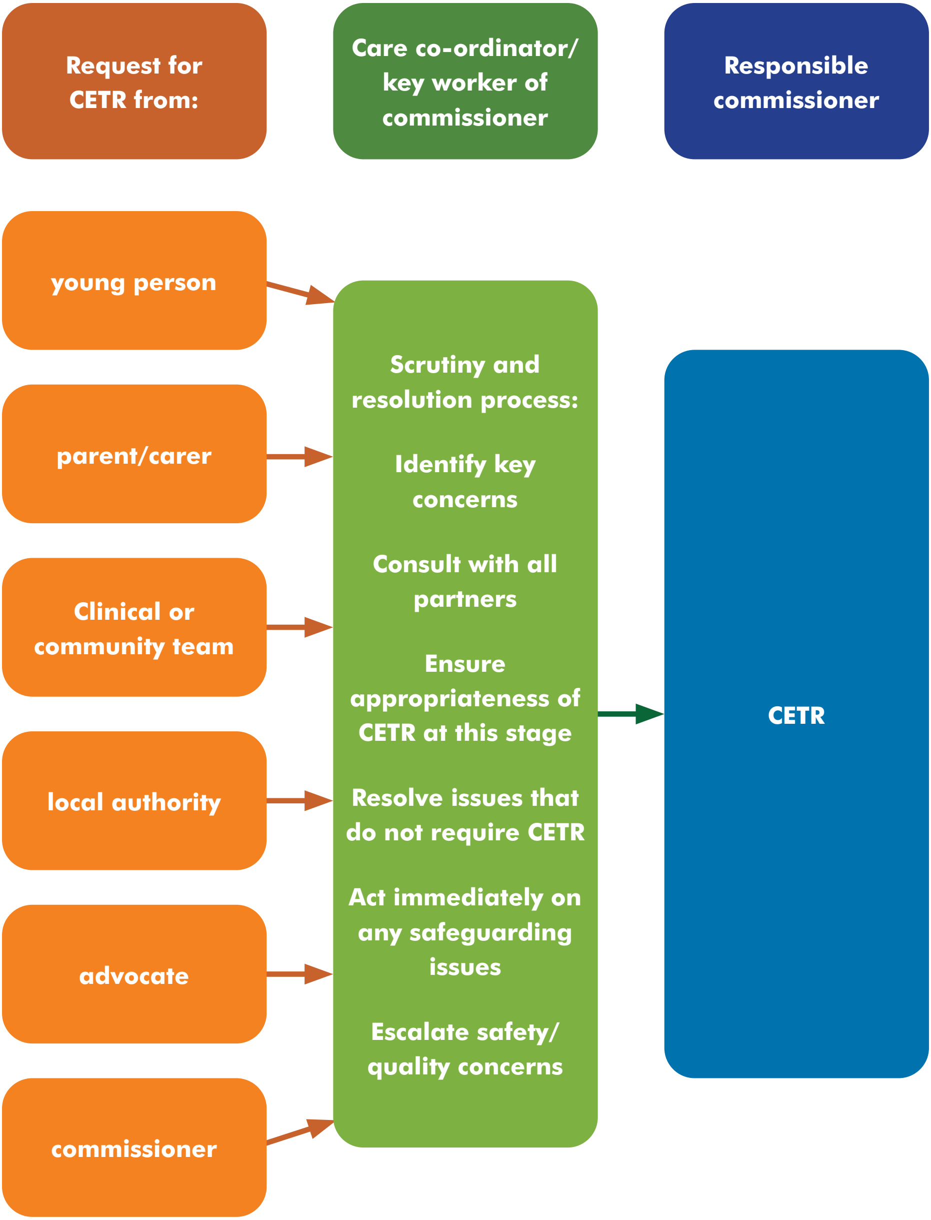
A review cannot take place without the consent of children or young people with capacity, or their parent/carers (or those with parental responsibility for the child).

For further guidance around consent see https://bit.ly/2HaLcv3 Section 3, page 14.

Requests for CETRs

Each area should have a clear policy about CETRs, the information available about them and how to request them. This information should be part of the Local Offer so that families and young people know about it, what to do and who to ask if they feel there is a risk of admission of a child or young person to a Tier 4 mental health setting. The information should explain how the community CETR process works and what needs to happen if someone is admitted to a Tier 4 setting.

If a child or young person is admitted to a mental health setting, a post admission CETR must be held within 2 weeks of admission if there has not been a Community CETR. Inpatient CETRs must then be held, if the child or young person remains an inpatient, every 3 months until discharge (see page 56 https://bit.ly/2lyCoqK)



Pathway for a CETR on request

Who carries out CETRs?

CETRs are carried out by an independent panel chaired by the commissioner responsible either from the local CCG (or from NHS England specialised commissioning). It is important those responsible for commissioning and providing services (this includes SEND services and schools) are present. The addition of "Education" to CTRs for children and young people reflected the vital importance of and right to education for all children and young people.

CETR process

Care Education and Treatment Reviews are designed around the child or young person and their person-centred plan and should focus on who they are, what they are good at and what they struggle with.

The CETR facilitates a process of looking for alternatives to admission (if possible) and if not, follows the child or young person through any subsequent admission or period of assessment/ treatment and towards discharge.

CETRs do not make the decisions on whether to admit or discharge a child or young person from hospital. This remains the responsibility of clinicians or indeed the courts/Ministry of Justice (Part 3 of the Mental Health Act).

Building the Right Support and CETRs is a core part of NHS England policy developed in conjunction with the Local Government Association, the Association of Directors of Adult Social Services, as well those using services and their families. It aims, along with the Transforming Care programme, to ensure that children and young people with a learning disability, autism or both, can live more independent lives in the community, with support, and closer to home, by ensuring that they:

- aren't admitted to hospital or Assessment Treatment Units unless they have an actual need,
- get the right help from community services (including CAHMS) and education to ensure their needs can be met within their local community (and have a CETR if they are at risk of admission),
- have their voice heard and are able to give feedback, raise concerns and make complaints about their and their CYP experiences,
- get out as quickly as possible and do not stay there when there is no longer any treatment being given, or they should not have gone in in the first place (for example because of a lack of community services) and
- are included on Dynamic Registers and at risk of admission registers to ensure they are getting the right person-centred care and support from all services.

Medication and other Treatment

STOMP: **S**topping **T**he **O**ver **M**edication of young **P**eople

STAMP: **S**upporting **T**reatment and **A**ppropriate **M**edication in **P**aediatrics

STOMP-STAMP is an initiative that was launched in December 2018 in response to research that highlighted the widespread inappropriate use of psychotropic medication in treating mental ill health in people with learning disabilities. This includes the continued use of mediation long after the original rationale for prescribing it has passed.

The **Long Term Plan** acknowledges that people with learning disabilities and autism are more likely to be prescribed psychotropic medication inappropriately.

Psychotropic medicines affect how the brain works and include medicines for psychosis, depression, anxiety, sleep problems and epilepsy. Sometimes they are also given to people because their behaviour is seen as challenging.

STOMP-STAMP aims to:

1. Make the lives of children and young people with a learning disability, autism or both, who are prescribed psychotropic medications, better.
2. Make sure that children and young people who need medication can get it for the right reason, in the right amount for as short a time as possible.
3. Help people to understand more about these medications and have the confidence to ask why they are needed.
4. Make more non-medication treatments and support available.
5. Make sure the person **with** their family and paid carers are involved in any decisions to start, stop, reduce or continue taking them.
6. Get more children and young people with a learning disability, autism or both to have an **annual health check** starting from the age of 14.

In addition to medication, the initiative recognises the importance of other therapies and support (including family support) and suggests that these should be offered before prescribing medication as well as while taking psychotropic medication.

Links to Further Information

Learning from deaths of people with a learning disability programme

https://bit.ly/2NqtZlh

Learning Disability Improvement Standards

https://bit.ly/2tzhOXz

Ask Listen Do

https://bit.ly/2Il681c
https://bit.ly/2KH94bx (a resource to help organisations in making conversations count)

Universal Personalised Care

https://bit.ly/2Mpg3YQ

Autism Care Pathway

https://bit.ly/2ZeexuH

Personal Health Budgets

https://bit.ly/2Hgvqyu

Annual Health Checks

https://bit.ly/2P4FrFz (easy to read information from Mencap)

https://bit.ly/2KTmuQL (a video for people with a learning disability)

https://bit.ly/2Z05mCF (Blog by Robyn Steward, an autism consultant and Autistic Ambassador for the National Autistic Society.)
https://bit.ly/2ILPpNz (Blog from Contact about engaging with GPs)

Care, Education and Treatment Reviews

https://bit.ly/2HaLcv3
https://bit.ly/2HaLcv3 (information for health and social care providers)

STOMP-STAMP

https://bit.ly/2MnJxGs

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INSTRUCTOR
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YOUTH MENTAL HEALTH FIRST AID

TWO DAY COURSES

ONE DAY YOUTH MENTAL HEALTH FIRST AID CHAMPION COURSE ALSO AVAILABLE

Youth Mental Health First Aid (MHFA) training is for anyone who works with, lives with or supports young people aged 8-18. This training helps the adults in a young person's life to have the skills and confidence to step in, offer first aid and guide them towards the support they need.

TWO DAY COURSE

By taking part in the Youth MHFA two day training course you will become **qualified** as a Youth Mental Health First Aider.

TO FIND OUT MORE AND TO BOOK

call the team on **01827 311 500**

visit **www.nasen.org.uk/YMHFA**

or email: **education@nasen.org.uk**

Youth Mental Health First Aiders have:

- An in-depth understanding of young people's mental health and factors that affect wellbeing;
- Practical skills to spot the triggers and signs of mental health issues;
- Confidence to reassure and support a young person in distress;
- Enhanced interpersonal skills such non-judgemental listening;
- Knowledge to help a young person recover their health by guiding them to further support;
- Ability to support a young person with a long-term mental health issue or disability to thrive;
- Tools to look after your own mental wellbeing.

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About NHS England

The NHS England Learning Disability and Autism programme is all about ensuring children and adults with a learning disability, autism or both have better health and life outcomes, in the community, with the right support, close to home.
Visit www.england.nhs.uk/learning-disabilities/ for more information.

About nasen

nasen is the leading UK professional association embracing all special and additional educational needs and disabilities. The organisation promotes the education, training, development and support of all those working within the special and additional educational needs and disabilities sector. Membership of nasen is an invaluable source of advice, offering an exclusive and vital range of benefits to support teachers, governors, teaching assistants and the entire education support network in the delivery of high-quality inclusive practice.

Visit www.nasen.org.uk for more information about what nasen can do for you.

ISBN 978-1-911656-01-2
9 781911 656012