NHS
North East London Commissioning Alliance

LEARNING DISABILITIES AND AUTISM TOOLKIT

CARE (EDUCATION) AND TREATMENT REVIEWS

North East London Boroughs

PREFACE

This toolkit has been created by the North East London Learning Disabilities and Autism Programme Team, in partnership with our local Clinical Commissioning Groups, to provide support and guidance to front line staff who work with people in the borough with learning disabilities and/or autism. We want to ensure that everyone working and living in North East London knows how to access additional support for those who might need it to remain safely supported in the community.

The North East boroughs include: Barking & Dagenham, City & Hackney, Havering, Newham, Redbridge, Tower Hamlets and Waltham Forest.

The focus of our local Dynamic Risk Registers and the Care (Education) and Treatment Reviews is always to ensure we avoid admitting people with a learning disability and/or autism to long stay mental health hospitals wherever possible. Key to this is providing intervention at the right time. As such we ask you to consider this toolkit when working with anybody with a learning disability and/or autism, of any age. Care (Education) and Treatment Reviews can be vital at times of crisis, but can also be equally effective in preventing a person reaching crisis point in the first place.

We hope you find this toolkit helpful, but we know that every individual is different. As such if you need any help or guidance with the Care (Education) and Treatment Review process, please do contact your local team whose details can be found in Appendix 3.

Thank you for taking the time to review this toolkit, and for working with us to continue to improve the lives of people with a learning disability and/or autism in North East London.

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WHAT ARE CARE (EDUCATION) AND TREATMENT REVIEWS?

Care (education) and treatment reviews were introduced in October 2015 as part of the Transforming Care programme led by NHS England.

Care and Treatment Reviews (CTRs) and Care, Education and Treatment Reviews (CETRS) are meetings about children, young people and adults with learning disabilities, autism or both, who are at risk of being admitted to, or are currently in, a specialist mental health or learning disability hospital. They are usually chaired by commissioners and are carried out by an independent panel of people, which is looked at later on in this toolkit.

The purpose of CTRs and CETRs are to improve the care people receive within the community and avoid unnecessary admissions and if people are admitted to hospital, that they are there for the shortest time necessary. Where an admission is felt to be needed the C(E)TR can be used to facilitate a planned admission. There are 4 questions that are looked at during a review:

1. Is the person safe?
2. Is the care they are receiving good?
3. What are their future care plans?
4. Can their care and treatment be provided within the community?

Please see **Appendix 1** at the end of this toolkit for further information on these questions.

Transforming Care Programme

The aim of this programme was to “improve the lives of children, young people and adults with a learning disability and/or autism who display behaviours that challenge, including those with a mental health condition.” (NHS England)

To read more about the Transforming Care Programme click here

Principles

The C(E)TR panel must ensure that the following principles are always applied:

- **Person centred and Family centred**
  The individual and their family are at the heart of the review and the panel must ensure that any care provided is done in a person and family centred manner.
- **Evidence Based**
  The panel should have access to all information required to help them understand the person's care and what is or isn't working.
- **Rights led**
  People should be treated as an equal partner in their own C(E)TR and their rights must be upheld.
- **Seeing the whole person**
  The C(E)TR should be a holistic process which sees the whole person not just their mental health or behaviour. The panel should take into consideration their quality of life, likes, dislikes, choices, hopes and fears.
- **Open, independent and challenging**
  Everyone on the panel has the right to speak up when something doesn't seem right about the person's care. Questions can be asked and recommendations made about changes required to the person's care.
- **Nothing about us without us**
  There should be as much involvement as possible of the person who the C(E)TR is about, including their family carers. This includes giving consent, getting prepared and taking part in the review and receiving a copy of the report after.
- **Action focused**
  Reports after the C(E)TR should have clear actions that are easy to understand, says who is responsible for each action and when they should happen by. The commissioner will keep an eye on these actions to ensure they are happening.
- **Living life in the community**
  C(E)TRs should be about helping people to be able to live well and safely in their communities. If they are in hospital the focus should be about whether they need to be there and whether they can be supported in the community

Benefits of C(E)TRs

Care (Education) and treatment reviews:

	Help improve the quality of care people receive within the community or in hospital
	Reduce the amount of time people spend in hospital
	Help find solutions to problems that are stopping them from leaving hospital
	Help people stay in their home and community with extra support where possible
	Empower people to be in control of their care and treatment by being involved in decision making
	Brings health and social care teams together to work collaboratively

During April 2016 - May 2018, 1904 community CTRs were carried out and in approximately three quarters of them a decision was made to not admit the individual to a hospital. (NHSE)

Before you move onto the next section please take some time to watch a video by NHS England called "Making a difference with CTRs" which looks at the benefits of them. Please click here to view the video

TYPES OF CARE (EDUCATION) AND TREATMENT REVIEWS

Community C(E)TR

A community C(E)TR takes place when someone is at risk of being admitted into hospital. This type of review will look at alternatives to admission and if further support can be provided within the community. Community C(E)TRs can be requested.

Please see Page 9 for the community C(E)TR process.

Inpatient C(E)TR

If someone is admitted to hospital they will have an inpatient C(E)TR. These will review the person's care and treatment, confirm that their hospital placement and treatment are appropriate and start to think about planning for discharge.

Inpatient C(E)TR Timeframes	
Post-admission C(E)TR	Should take place within 10 working days of admission for children and 28 calendar days for adults if no community C(E)TR has taken place
Inpatient C(E)TR	Should take place: • Every 3 months for children and young people • Every 6 months for adults in non-secure setting • Every 12 months for adults in secure settings • Or upon request

Consent

It is important to remember that individuals need to give consent to having a C(E)TR otherwise they cannot take place. If any adults do not have capacity to make a choice then a decision needs to be made in their best interest.

Parents or responsible carers will have to give consent for a child under 16 to have a CETR.

A consent form can be found on page 7 of the CTR Planner on the NHS England website. Click here to view

Local Area Emergency Protocol

The Local Area Emergency Protocol (LAEP) is raised when an individual with learning disabilities and/or autism has been or is likely to be recommended for inpatient admission with little or no notice meaning a community C(E)TR has not taken place.

A LAEP review will take place if:

- The individual has been assessed under the Mental Health Act as requiring admission and there has been no time for a C(E)TR
- The individual is in crisis and admission has been recommended before a C(E)TR can be arranged
- The individual is in crisis outside of hours and a panel can not be made available for a C(E)TR

See **Appendix 2** for further information on the local area emergency protocol.

Care, Education and Treatment Review

A care, education and treatment review (CETR) is similar to a care and treatment review but involves other professionals from health, education and social care who all support a child or young person with a learning disability and/or autism if aged under 18.

Where possible the child or young person should always be involved in the review and contribute to the actions. The child or young person's parents/carers should also be involved in their review.

DYNAMIC SUPPORT REGISTERS

The Dynamic Support Register, or Enhanced Care and Support List (ECSL), is a register of people with learning disabilities and/or autism who may need higher input from services and who may be at risk of being admitted to a specialist or mental health hospital. The register will help local support teams to identify those who would benefit from a C(E)TR.

Each local borough holds a register for adults and one for children's and young people. Please see **Appendix 3** for your local borough contacts.

Who should go on the Dynamic Support Register?

An individual should be added to the register/ECSL if they meet one or more of the following criteria that can put them at a higher risk of being admitted. Signs of being at risk of admission will be different for every individual.

Signs of being at risk of admission

- Increase in behaviours that challenge or other incidents;
- Engaging in offending behaviour;
- Police involvement;
- Attendance at A&E;
- Provider or family saying they can't cope or requesting a new placement
- Non-compliance with medication and non-attendance at appointments with professions
- Significant life changes, such as a move or bereavement
- Alcohol or substance misuse
- Previous history of admission
- Moving away from support plan or any conditions for living in the community, e.g. individual is on bail or under a community treatment order

Please see **Appendix 4** for the full list.

Consent

Individuals must give consent for their details to be held on the register. If they do not have capacity then consent should be obtained from the person who has legal power. Parents/carers must provide consent for children to be added to the register.

The register holder will decide who is responsible for obtaining consent. In most cases this will be the professional who knows the individual the best, e.g. their social worker.

Consent forms and letters can be requested from your local borough register holder

Who can add someone to the register?

The following teams/services/individuals can identify and input information into the register/list:

- Health and social care teams
- Youth offending teams
- Local police/teams who work with the criminal justice system
- Residential schools
- Residential and supported living providers
- Family members/carers
- Any other groups/teams

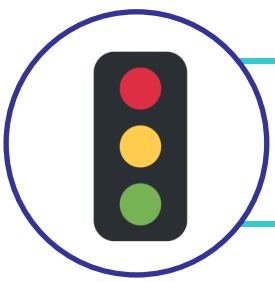
How to add someone to the register

Each borough will hold their own registers/lists.

Speak to your register holder to confirm the individual should be added to the register

Provide individual/family with easy read information about the register

Obtain consent from the individual or on behalf of them



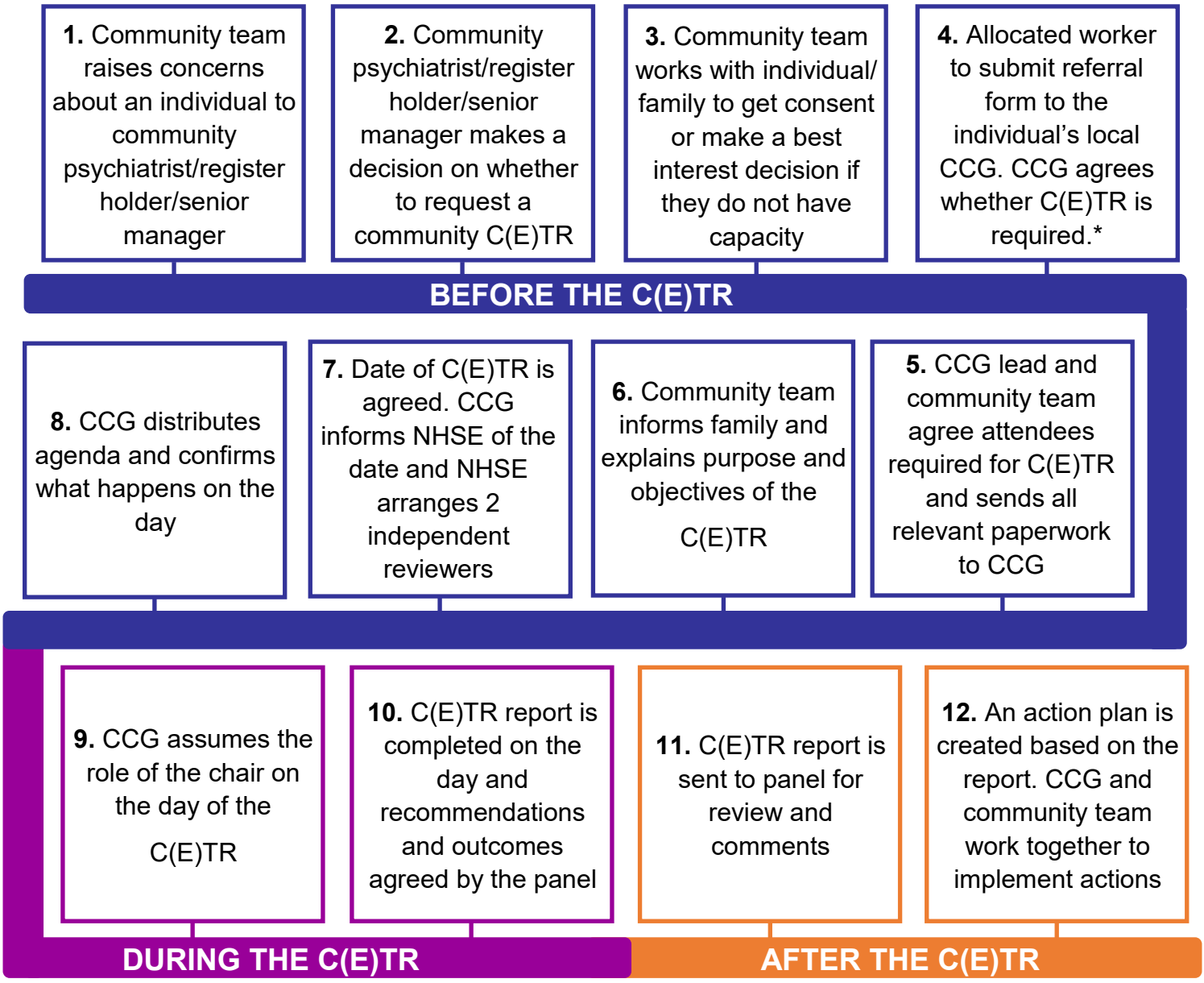
Discuss the case with the register multi-disciplinary team and RAG rate the case

Please see **Appendix 5** for the Risk Level Tool which explains how to RAG rate a case.

COMMUNITY C(E)TR PROCESS

A C(E)TR can be requested by the individual, their family or any other professional involved in providing care.

The following shows the process when requesting a community C(E)TR:



Please approach your CCG lead to confirm your local contacts and referral process. Please see pages 11-12 for more information about what happens before, during a after a C(E)TR.

* If a C(E)TR is not appropriate the CCG lead will discuss other appropriate options with the community team such as calling a Multi Disciplinary Team meeting or signposting to community services.

Before you move onto the next section please take some time to watch a video by NHS England called "CTRs and being person centred" which looks at the focus on the person. Please click here to view the video.

ROLES AND RESPONSIBILITIES

The C(E)TR is carried out by an independent panel which includes a CCG commissioner, expert by experience and clinical reviewer. There will be other people present on the day including the individual themselves and/or an advocate. The following gives a brief overview of who may be present and what their role is:

The individual; their advocate; family member(s); carer(s)
Role - to provide their thoughts about the care and treatment and potential options.

CCG Commissioner
Role - ensures the smooth running of the review meeting by acting as the chair, including writing up the report.

Expert by Experience
This will either be a person with a learning disability/autism or a family carer. Role - to use their lived experience to ensure the individual's voice is heard.

Clinical Expert
This is someone who is qualified to work in health care such as a nurse or psychiatrist. Role - to provide a clinical perspective to the review.

Multidisciplinary Team
May include the social worker; clinical professionals; provider; or education representatives. Role - to share information about current care and contribute to recommendations and suggested actions.

Both the expert by experience and clinical expert are not known to the individual who the review is about and are not affiliated with Health, CCG or local authorities so they provide an impartial perspective.

NHS England are responsible for C(E)TRs that take place in low/ medium/high secure services and any children in Tier 4 beds. NHSE also oversee C(E)TRS across the country and are a key partner for ensuring they are delivered.

For further information about the CAHMS Tier structure please click here.

BEFORE, DURING AND AFTER THE C(E)TR

Once the C(E)TR meeting has been set up as per the process chart on page 9, the following is a brief overview of what must happen before, during and after the review including a list of paperwork required:

BEFORE

- ✓ The process is explained to the individual and their family/carers using the My Care and Treatment Review easy read guide by NHSE.
- ✓ The CTR planner is completed with the individual which includes a consent form and helps them to express their needs and any issues. Consent must be obtained in order for the C(E)TR to go ahead.
- ✓ Any reasonable adjustments required for the day needs to be communicated to the chair as soon as possible.
- ✓ All necessary documents about the individual must be sent to the chair the week before the review. Please see appendix 5 for a list of documents.
- ✓ The documents and agenda will be sent to experts a day before the C(E)TR date to ensure all documentation is read in time. This may vary per borough so please check with your local commissioner if unsure.

DURING

- ✓ The individual should be supported with taking part in their review in a way that suits them. E.g. this may mean they meet panel members separate to everyone else or individually.
- ✓ The agenda will be followed as closely as possible.
- ✓ The Key Lines of Enquiry template will be completed by the chair and findings and recommendations will be agreed with panel members.
- ✓ Feedback of findings and recommendations will be given to everyone involved in the C(E)TR in jargon free language.
- ✓ Actions, timescales and who will be responsible for each action will be agreed.
- ✓ The chair will be responsible for putting together the report and it will be agreed in the meeting who will be responsible for ensuring the overall action plan is carried out. The responsible person is usually the commissioner/chair of the C(E)TR unless agreed otherwise.

AFTER

- ✓ The final report and action plan is sent to all necessary people within 10 working days of the review.
- ✓ The individual must be supported to fill in the feedback form in their C(E)TR planner booklet and copies sent to the Chair.
- ✓ Actions should be carried out by the dates given and any barriers to this should be addressed. Actions should be reviewed in a care meeting, e.g. CPA, within 3 months of the C(E)TR.
- ✓ Some boroughs may arrange a professional's meeting a month after the C(E)TR to check on progress and identify any problems or barriers.

DOCUMENTS REQUIRED

The following documents are the ones that should be prepared in advance of the C(E)TR meeting and put into a pack for the panel:

- ➤ Risk Assessments
- ➤ Most recent Mental Health Act Tribunal report
- ➤ Social circumstances report
- ➤ Safeguarding reports from the last year
- ➤ Health Action Plan
- ➤ Positive Behaviour Support Plan and other care plans
- ➤ Communication Passport
- ➤ Medication Chart
- ➤ Ministry of Justice documents, where appropriate
- ➤ Care Programme Approach plans and meeting minutes
- ➤ Mental Health Act papers
- ➤ Community service specification and/or discharge plan
- ➤ Last 4 weeks of progress notes
- ➤ Incident forms where restraint was used, either since admission or last CTR
- ➤ Person Centred Care Plan
- ➤ Education, Health and Care Plan
- ➤ Hospital Passport
- ➤ Mental Capacity Assessments
- ➤ Activity Planner

The C(E)TR chair will be responsible for ensuring that all written and verbal information provided will be kept private and confidential.

For a C(E)TR in a hospital the responsibility for producing the pack is with the provider.

VIRTUAL C(E)TRS

Due to the current situation with coronavirus and restrictions it will not always be possible to carry out face to face C(E)TRs. However it is still really important to continue to offer reviews as best as possible. Therefore C(E)TRs are currently taking place virtually either via a video meeting or phone.

It is important that the process is discussed with the individual and their families/carers as speaking over the phone or computer may be quite daunting for some people. Therefore, you will need to work with them to find out what the most suitable method is for them and any reasonable adjustments that they may require.

The following are some key points from the revised NEL CETR guidance COVID19 document:

- ✓ Commissioners will direct the format of the C(E)TR and this should take into consideration the preferences of the patients and availability of technology.
- ✓ Patients and their family should be invited to join the C(E)TR where possible.
- ✓ If patients are not comfortable with using technology the commissioner will work with people who know the patient well to think about alternative ways they can be involved.
- ✓ Patients should be sent a copy of the easy read guide to virtual C(E)TRs and a visual list showing who will be at the meeting and what their role is.
- ✓ The C(E)TR planner should still be completed with the patient before the review and sent to the chair. Click **here** for the revised CETR planner to use during this time.

Virtual C(E)TR documents

Click on the titles below to view related documents:

- **NEL CETR Guidance COVID19**
- **Virtual CTR Easy Read**
- **Virtual CTR who's who template**

CASE STUDIES

Now that we have looked at what Care (Education) and Treatment Reviews are and what they involve let's have a look at how they have made a difference to some individuals. Please note names have been changed for confidentiality purposes.

COMMUNITY CTR

- George is an adult with autism and learning disabilities. He had lost a lot of weight and became very ill due to a behavioural compulsion to vomiting numerous times a day.
- A CTR was arranged which included all those who were involved in George's care and support; his family; leading Gastroenterology consultants; positive behaviour support specialists and NHSE.
- An action plan was put in place which addressed all George's needs and ensured engagement with other health specialists within and out of the UK who could support clinicians in his care.
- A short time after interventions were put in place there was a marked improvement in George's behaviours.
- Outcome: George is now a more healthier weight and a lot happier. He is more engaged with the care and support team around him. His vomiting has reduced from 20-25 times a day to less than 3 times a week. And he is now able to go out into the community which he enjoys especially if he is in a car.

INPATIENT CTR

- Diego is an adult with a diagnosis of Coffin-Lowry Syndrome, Klinefelter Syndrome, Asthma, incontinence and mild learning disabilities who was living in the community in supported living.
- His mum was struggling to provide support due to also caring for his sibling with complex disabilities.
- Diego's grandparents provide support with meals and managing finances.
- Diego had a generic social worker but was not engaging with them or the community learning disability team (CLDT). He didn't want to live in his placement due to issues with another resident.
- A violent episode and property damage led to him being admitted into hospital.
- An inpatient CTR was carried out and during the review the family expressed they wanted psychology input and a better placement.
- Outcome: Diego was allocated a learning disability social worker and received input from the CLDT. It was arranged for him to move to a different placement. The family expressed that they felt listened to and supported and Diego did not have a prolonged admission. Diego is currently not on the dynamic risk register and is doing well in his new placement.

USEFUL DOCUMENTS

My CTR Planner

https://www.england.nhs.uk/wp-content/uploads/2017/03/my-care-treatment-review-symbol-edit.pdf

*Professionals should note that the C(E)TR consent form can be found on page 7

Care and Treatment Reviews: A family survival guide

http://bringingustogether.org.uk/wp-content/uploads/2017/08/CTR-Survival-Guide-Aug-2017-1.pdf

NHS England C(E)TR Policy

https://www.england.nhs.uk/wp-content/uploads/2017/03/ctr-policy-v2.pdf

NHS England C(E)TR Policy (easy read)

https://www.england.nhs.uk/wp-content/uploads/2017/03/easy-read-care-treatment-review-policy.pdf

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APPENDIX 1 - KEY LINES OF ENQUIRY

In common with the approach taken by the Care Quality Commission, the CTR policy will use Key Lines of Enquiry (KLOE) to guide and structure the review process.

Each KLOE consists of a key questions following by examples of probe questions that reviewers can use to explore and gather information on the issue under discussion. Each KLOE will also suggest sources of evidence that the review team might look for or ask to be provided to substantiate their findings.

The Key Lines of Enquiry will provide information and evidence to enable a summary and feedback for the person that says:

- Am I safe?
- What is my current care like?
- Is there a plan in place for my future?
- Do I need to be in hospital for my care and treatment?

The 10 KLOEs that a CTR seeks to address are:

1. Does the person need to be in hospital?
2. Is the person receiving the right care and treatment?
3. Is the person involved in their care and treatment?
4. Are the person's health needs known and met?
5. Is the use of any medicine appropriate and safe?
6. Is there a clear, safe and proportionate approach to the way risk is assessed or managed?
7. Are any autism needs known and met?
8. Is there active planning for the future?
9. Are family and carers being listened to and involved?
10. Are the person's rights and freedoms being protected and upheld?

For more information about KLOE please see the NHSE Care and Treatment Reviews Policy and Guidance document by clicking here.

APPENDIX 2 - LOCAL AREA EMERGENCY PROTOCOL

The LAEP relates to people of all ages with learning disabilities and/or autism who are at risk of admission to a specialist learning disability or mental health inpatient service. The protocol is invoked only when an individual has been or is likely to be recommended for admission with little or notice, in particular outside of standard working hours.

This protocol excludes those patients where the route into hospital is through the Courts or from prison.

The following are key points from the full LAEP guidance document. If you wish to see the full guidance please email nel.lda@nhs.net for a copy.

When to hold a LAEP Review

If possible, the individual with learning disabilities and/or autism should always have a community Care (Education) and Treatment Review (C(E)TR) prior to admission.

A LAEP review can be called in place of a C(E)TR in the following circumstances:

- If the individual has been assessed under the Mental Health Act as requiring inpatient admission, and there is not enough time to convene a C(E)TR;
- If the individual has presented in crisis (e.g. to A&E) and inpatient admission is likely to be recommended before a C(E)TR can be arranged;
- If the individual has presented in crisis out of hours, and the CCG with not have a commissioner available to convene a C(E)TR.
- If the person has had a community C(E)TR is the 28 days prior to admission, a LAEP review will not be necessary.

Consent

The LAEP protocol will be with the explicit consent of the individual, or when appropriate a person who holds parental responsibility for them.

If the person lacks capacity, a best interest decision making process should be carried out, unless the person has a representative with lasting power of attorney for health and wellbeing that can make the decision on their behalf.

If consent is refused, confidential information can still be recorded and shared to help a person who may be at risk of harm.

APPENDIX 3 - LOCAL BOROUGH CONTACTS

Barking and Dagenham, Havering and Redbridge CCGs

Transforming Care Team:
Jennifer Hibben, Transforming Care Lead (Operational)
Lindsey Levison, Project Support Officer
Jazz Mann, Project Support Officer
Email: bhr.tcp@nhs.net

Barking and Dagenham Local Authority

Commissioner
Clare Brutton
Senior Commissioning Manager, Commissioning Adults Care and Support
Tel: 020 8227 3775
E-mail: clare.brutton@lbbd.gov.uk

Adult Register Holder
Dr Ehab Khattab
Consultant Psychiatrist, Barking & Dagenham All Age Disabilities Service
Tel: 020 8227 5432
E-mail: Ehab.Khattab@nelft.nhs.uk

Children Register Holder
Sharon Stapleton
Email: Sharon.stapleton@lbbd.gov.uk

Havering Local Authority

Commissioner
Sam Saunders
Commissioning Programme Manager
Tel: 01708 433441
E-mail: Sam.Saunders@havering.gov.uk

Adult Register Holder
Dr Bini Thomas
Consultant Psychiatrist, Havering Community Learning Disabilities Team
Tel: 01708 434188
E-mail: Bini.Thomas@nelft.nhs.uk

APPENDIX 3 - LOCAL BOROUGH CONTACTS

Children Register Holder

Alan Thorne
CAD Social Work Team and Preparation for Adulthood
Tel: 01708 434460
E-mail: Alan.thorne@havering.gov.uk

Redbridge Local Authority

Commissioner

Bradley Ramsey
Strategic Commissioner for Learning Disabilities, Mental Health and Transforming Care Programme
Tel: 0208 708 5171
E-mail: Bradley.Ramsey@redbridge.gov.uk

Adult Register Holder

Dr Rehana Akther
Consultant Psychiatrist in Intellectual Disabilities, Community Health & Social Care
Tel: 0208 708 7168
E-mail: rehana.akther@nelft.nhs.uk

Children Register Holder

Gloria Samuel
Service Manager, Fostering, Adoption and Disabled Children Service
Tel: 0208 708 6060
E-mail: Gloria.Samuel@redbridge.gov.uk

City and Hackney CCGs and Local Authority

Commissioner
Sarah Darcy
Children and Young People's Strategic Lead
E-mail: sarah.darcy1@nhs.net

Children Register Holder

Ellie Duncan
Programme Manager
Tel: 020 3816 3082
Email: e.duncan1@nhs.net

Adults Register Holder and Joint Commissioning Officer
Rebecca Harkes
Joint Commissioning Officer for Learning Disabilities, London Borough of Hackney/City and Hackney CCG
Tel: 020 8356 8140
Email: rebecca.harkes@hackney.gov.uk

APPENDIX 3 - LOCAL BOROUGH CONTACTS

Newham CCGs and Local Authority

CCG Commissioner
Gary Woolvett
Senior Commissioning Manager Learning Disabilities and Autism
Newham CCG
Telephone: 0203 816 3607
Email: gary.woolvett1@nhs.net

Local Authority Commissioner
Melissa McAuliffe
Commissioner
Telephone: 020 3373 3067
Email: Melissa.McAuliffe@newham.gov.uk

Adult Register Holder
Robin Betts
Clinical Service Manager
Newham Health Team for Adults with Learning Disabilities
Telephone: 0207 059 6600
Email: elt-tr.NewhamLD@nhs.net

Children's Register Holder
Matthew Richardson
Joint Senior Commissioning Manager
Children & Young People's Emotional Wellbeing & Mental Health, Newham CCG
Tel: 07717 516254
Email: matthew.richardson3@nhs.net

Tower Hamlets CCGs and Local Authority

Commissioner
Megan Clavier
Learning Disability Commissioning Manager
NEL CCG
Tel: 07341
Email: megan.clavier@nhs.net

Children's Commissioner and register holder
Diana Viscusi
Transformation Manager
Tower Hamlets CCG
Tel: 07717 516895
Email: diana.viscusi@nhs.net

Adults Register Holder
Hilary Evans
Team Manager, Mental health and Behavioural Support
Community Learning Disability Service
Tel: 020 7771 5535
Email: hilary.evans4@nhs.net

APPENDIX 3 - LOCAL BOROUGH CONTACTS

Waltham Forest CCGs and Local Authority

Commissioner
Laura Power
Integrated Commissioning Manager for Learning Disabilities
Waltham Forest CCG & London Borough of Waltham Forest
Tel: 07423 507286
E-mail: Laura.Power@walthamforest.gov.uk

Children's Commissioner and register holder
Katy Briggs
Head of Integrated Commissioning (Children's and Maternity)
Waltham Forest CCG
Tel: 07435 804146
Email: katy.briggs@nhs.net

Adults Register Holder
Dr Iparragirre Boni
Consultant Psychiatrist in Intellectual Disabilities
Community Health, NELFT
Tel: 020 8928 8300
Email: Boni.Iparragirre@nelft.nhs.uk

Specialised Commissioning

Adult Case Lead
Donna Steadman
Adults Case Lead Transforming Care – Specialised Commissioning
Tel: 020 8702 5400
E-mail: d.steadman@nhs.net

Children Case Lead
Reshad Nunhuck
CAMHS Case Manager Transforming Care – Specialised Commissioning
Tel: 07702 412444
E-mail: r.nunhuck@nhs.net

NEL CCGs

Learning Disability and Autism Programme Team:
Rachel Penney, Strategic Lead
Mahsuma Choudhury, Project Manager
Beatrice Kivengea, LeDeR Progamme Officer
Harpreet Jutle, Project Officer
Email: nel.lda@nhs.net

APPENDIX 4 - SIGNS OF RISK OF ADMISSION

The factors below may indicate that an individual is at risk but, in themselves, do not automatically warrant an individuals' details being added to the dynamic support register/enhanced care and support list. Therefore professionals should use their judgement and consider whether the person meets one or more of the following criteria, if so their details should be added to the ECSL:

- Identified for pre-admission or community C(E)TR
- Identified for or under the CPA process
- Under the care of behavioural/early intervention service, e.g. youth offending
- Recently discharged from hospital
- Young people of transition age in residential school placement
- Presented 'in crisis' at A&E departments
- Under the Home Treatment Team (HTT)
- Presenting with significant behavioural challenges
- Being supported in an unstable environment or concerns about longevity of the placement
- Quality concerns or safeguarding alert has been raised
- Significant life event and/or change, e.g. bereavement/historical abuse/moving home
- Has no family carers/advocates
- Consideration to living circumstances and any risks posed to other members of the family
- No effectively planned transition from child to adult services
- Child or young person who has been excluded from school
- Subject to regular and/or prolonged restrictive practices
- Has been in contact with the Criminal Justice System
- Has drug and alcohol addiction problems
- Has unstable/untreated mental illness
- Previous history of admission(s)
- Not previously known to services
- Non-compliance with medication
- Not attending/being brought to appointments
- Looked after children

This is not an exhaustive list and clinical judgement should be used to assess whether an individual is in need of enhanced support and therefore qualifies to be added to the register/list outside of the reasons stated above.

APPENDIX 5 - RISK LEVEL TOOL

This is a tool to consider the level of risk that an individual is presenting with. However we acknowledge that everyone's circumstances will differ and the user should use professional judgement alongside this tool to determine the level of risk.

The following has been defined as levels of risks:

RED
RISK OF ADMISSION: IMMINENT

- Individual is at imminent risk of needing an inpatient admission due to serious risk of harm to themselves or risk to others.
- Individual is at imminent risk of needing an inpatient admission due to serious risk of harm to themselves or risk to others.
- Individual presenting 'in crisis' at Accident and Emergency Departments.
- Individual's community placement is breaking down and situation is irretrievable leading to the individual or others being placed at significant risk.
- Individuals recently discharged from inpatient units including forensic (within 4 weeks of discharge).

AMBER
RISK OF ADMISSION: MEDIUM

- Individual requiring active intervention from multi-disciplinary team (MDT) and on CPA but not at imminent need for inpatient admission.
- Individual's community placement is breaking down however the situation can be resolved and risks to individual and/or others is not significant.
- Individual has heightened challenging behaviour which has also increased in frequency posing additional risks to the individual and/or others.
- Individual is showing signs of relapse in mental health including drugs and alcohol where there are identified risks.
- Individual in contact with police or presenting at Accident and Emergency.
- Individual not previously known to service
- Individuals discharged from inpatient units including forensic within the last 6 months (excluding those discharged in the last 4 weeks).

GREEN
RISK OF ADMISSION: LOW

- Individuals with chronic mental health requiring input from CLDT/CMHT with no imminent risks.
- Young Adults that have transitioned from children services in the last 3 months who have been in 48/52 week residential school placements or have not had an effective transition plan and therefore real risks are unknown.
- Individuals who have been discharged from inpatient units including forensic within the last 6 - 12 months who appear to be stable.