

Learning Disabilities and Autism Programme

NHS England – London Region

For the London Forum January 2023

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NHS England works with other health and care organisations to look after the running of the NHS, including NHS services for people with a learning disability and/or autism.

Some people will have a learning disability. Some people will have autism. Some may also have a **mental health** problem.



Mental health means how you feel and how your feelings affect you.

A **mental health** problem is a problem with someone's mind. It makes it difficult to cope with feelings.

Aims of the Programme



- support people with a learning disability and autistic people to live independently at home.



supporting people with a learning disability and autistic people to be **healthier** and **more independent**.

Numbers of people in hospital



- At the start of the “Transforming Care” Programme there were 360 patients from London in hospital.
- At the end of November 2022, there are 261 patients from London in hospital.
- 225 patients in hospital are Adults
- 36 patients in hospital are Children or Young people
- The plan at the end of March 2024 is for no more than 231 patients in hospital

Programme progress – Total number of inpatients

398



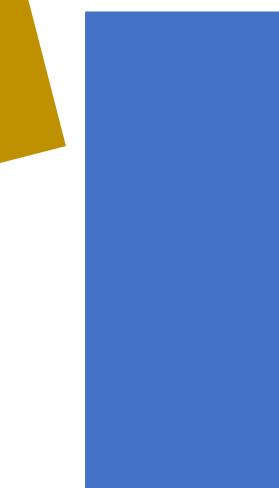
137 (34%)
Reduction

261



30 (11%)
Reduction
to go

231

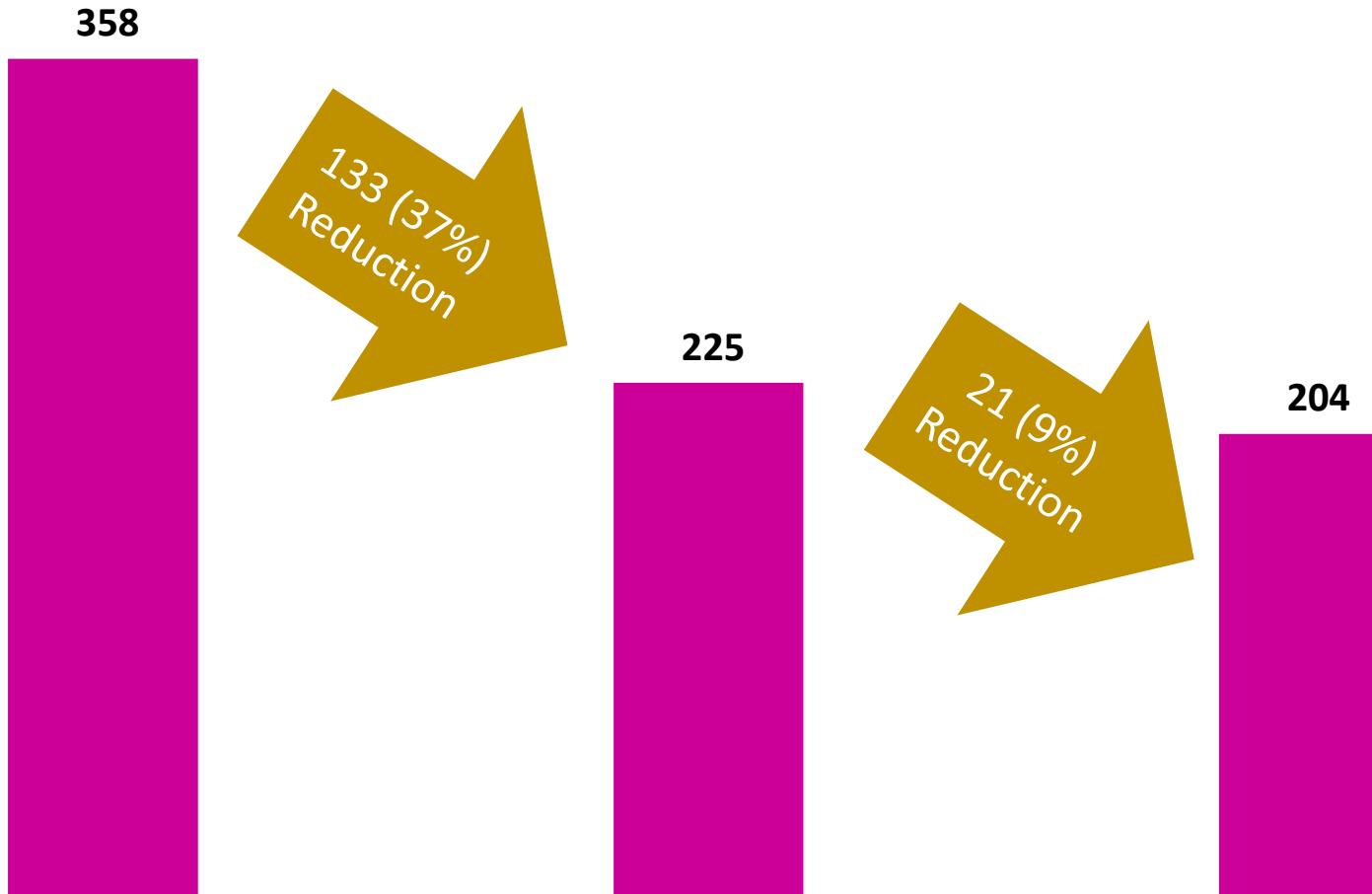


Where we started from
(Mar 2016)

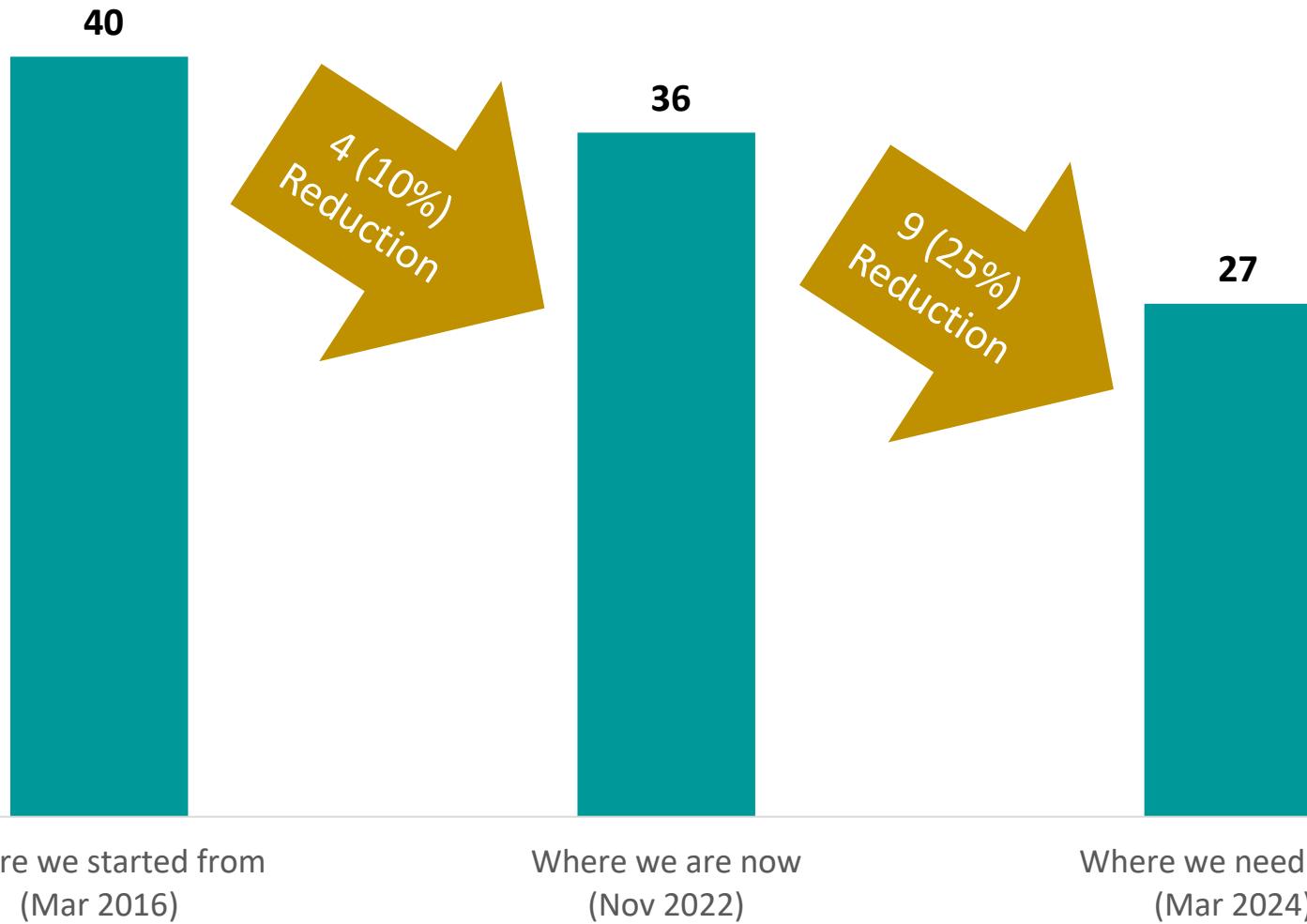
Where we are now
(Nov 2022)

Where we need to be
(Mar 2024)

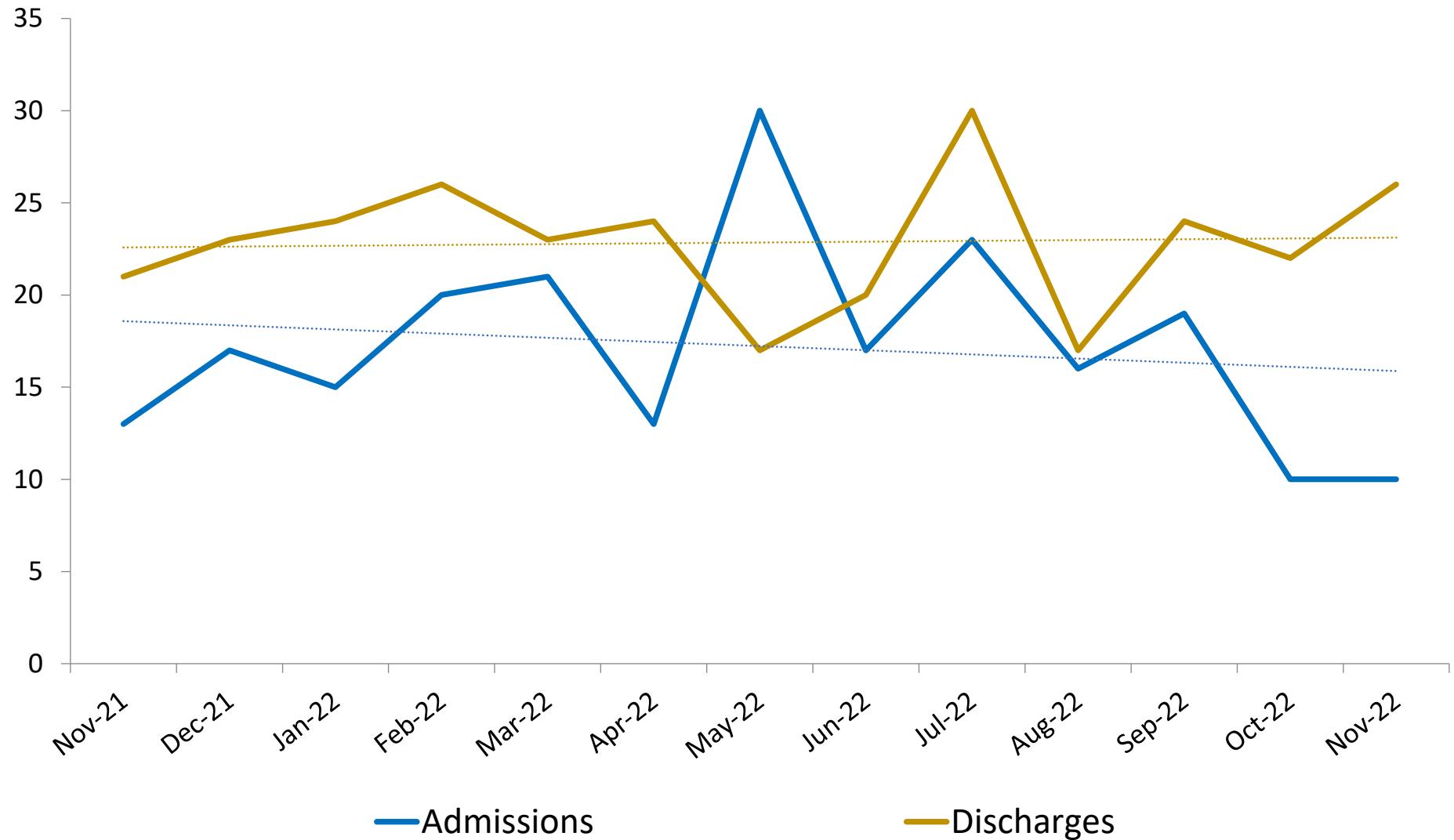
Programme Progress – Adult Inpatients



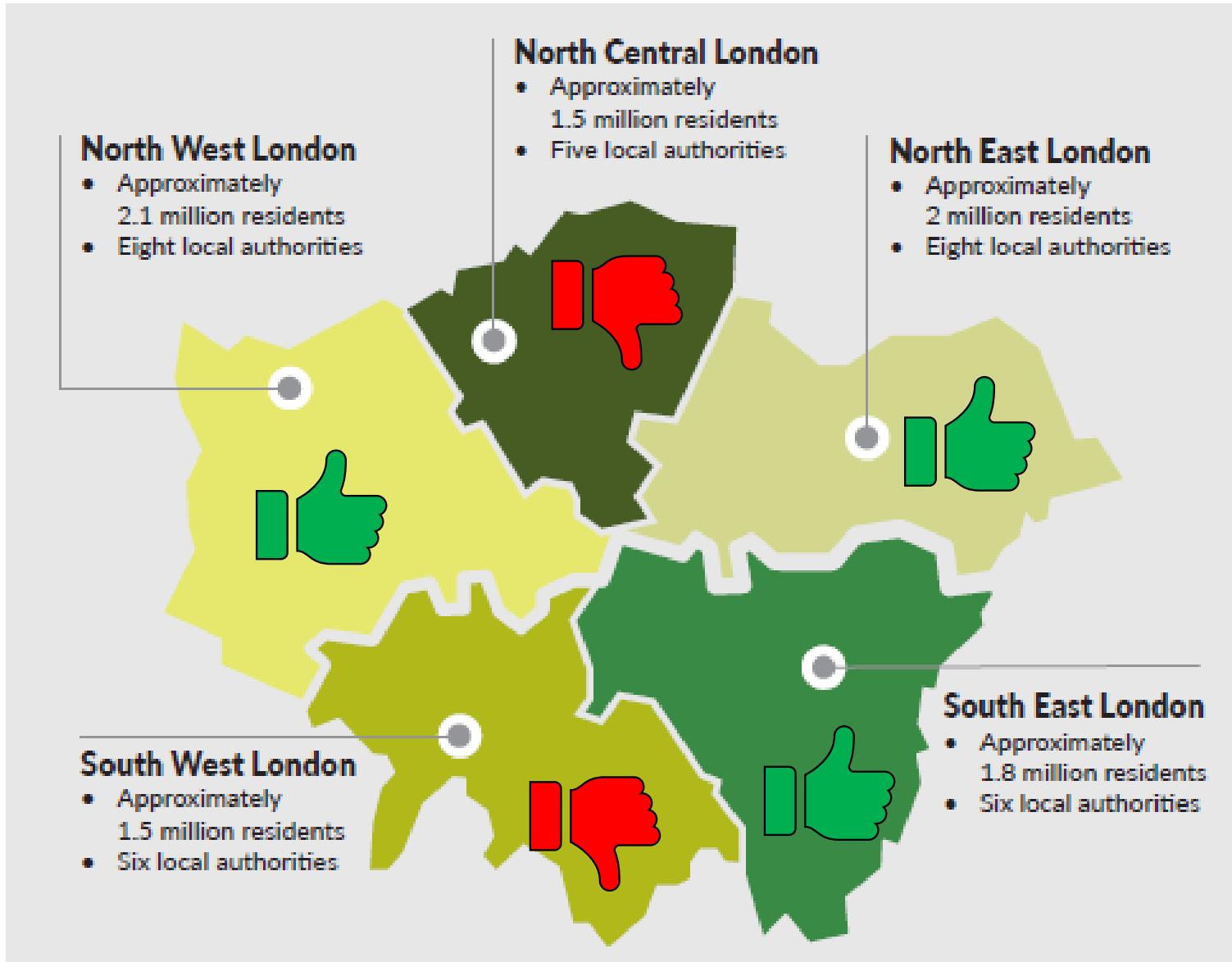
Programme Progress – Children and Young People Inpatients



Admission and discharges



Inpatient position by Integrated Care Systems



Learning from Deaths Reviews (LeDeR)

The **LeDeR** programme:



- **looks into** the deaths of people with a learning disability

The name of the programme has been changed to “Learning from lives and deaths” although people still use “LeDeR” for short.

In the past year the programme has also been looking at reviewing deaths of autistic people without a learning disability, although a lot of people do not say they are autistic and therefore it is not always recorded.

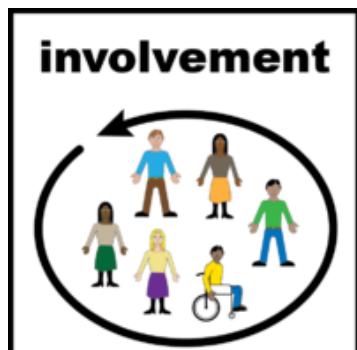
How is London doing on LeDeR?



- London is often the best performing region in England for getting the reviews done on time. The target is **95%** and London regularly gets **97%**
- We have been supporting the Integrated Care Boards to implement the new LeDeR policy.



- **BUT** a quality audit has told us that the reviews need to be better and more thorough
- **SO** we will continue to work towards:
 - ensuring people with a learning disability, autistic people and their family carers are involved in LeDeR across the Integrated Care System
 - improving the quality of some reviews to ensure that we get the best learning

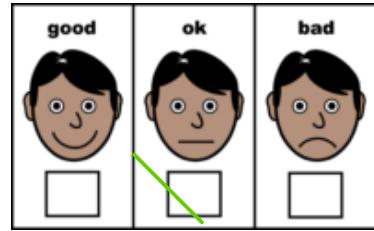


Care (Education) and Treatment Reviews (CETR)

- A C(E)TR is a review to make sure everything is going well and to see if anything could be better.
- A person with a Learning Disability or autistic person has a right to a C(E)TR if:
 - they are at risk of being admitted to a mental health, learning disability or autism hospital – a community C(E)TR, or
 - if they have been admitted to one of these hospitals – a post-admission C(E)TR, or
 - They have been in hospital for sometime and the C(E)TR will need to be repeated.
 - A person or their family can also request for a C(E)TR to be carried out if they think things could be going better than they are.



How is London doing on C(E)TRs?



- People are not getting C(E)TRs as soon as possible after they have been admitted to hospital
- We need to ensure that people have a CETR after they have left hospital.
- In London, we have made good improvements in doing “repeat” C(E)TRs for people who have been in hospital for a while

What are we going to do?

Improving the process across London to ensure that the CETR is personalised

Support the roll out of the new C(E)TR policy

Ensuring that recommendations from care education and treatment reviews are followed up and completed

Supporting a clinical contract pilot in London



Quality



A Commissioner is a person responsible for planning and paying for NHS care.

Each specialist hospital is assigned a “**Host Commissioner**” to support oversight of mental health hospitals where people with a learning disability or autistic people are. The guidance on how this can work better is being reviewed.

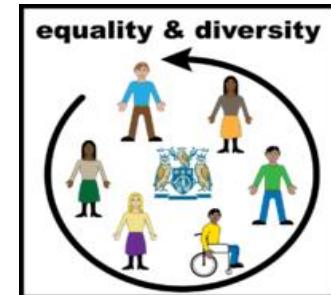
We are looking at how commissioners should help when they are concerned about a persons care in hospital.

To help health staff in London to care well for people with a learning disability and autistic people we are offering more training, especially around autism (Oliver McGowan training).



Next year we want to do more by:

Making sure all people get equal access to health care and support by championing the rights of people with a learning disability and autistic people form all ages, ethnicities, genders and backgrounds





STOMP is a project in England to stop the over use of psychotropic medicines.

These medicines are used to treat mental health conditions. Sometimes they are given to people when their behaviour is seen as challenging.

People with a learning disability, autism or both are more likely to be given these medicines than other people.

These medicines are right for some people but sometimes there are other ways of helping people so that they need less medicine or not at all.

STAMP stands for Supporting Treatment and Appropriate Medication in Paediatrics

Pharmacy teams around London have been doing some very good work.

This year NHS England in London has dedicated extra resources to help each Integrated Care System make progress and to understand how London is doing and what we should do next.



Diagnostic waiting times



- We have started to map out all of the places in London where someone can get an autism diagnosis. We want to understand where in London people are waiting the longest for an assessment. We have developed Support to help people stay as healthy and well as possible while waiting for an assessment.
- **Next Steps:** We will be working to reduce the length of time people that people have to wait to receive an autism diagnosis.

- We have taught GPs, who are giving **Annual Health Checks** to Autistic people, how to work best with autistic people.
- We have given training to employers on how they can best support their autistic colleagues.
- We have worked with **gender identity** and **maternity services** to improve their understanding of autism and create more accessible services.
- **Next steps:** we are going to give a conference on **digital tools** that can support autistic people in London. We will work with services that work with **homeless people** to improve their understanding of autism and create more accessible services.

Engagement and upskilling



Autism workstream continued



Employment and education



We have made a pledge that London employers can sign to show their commitment to improving their workplace for neurodiverse people that they work with. We have also delivered the first year of the **Autism in Schools Project**.

Next steps: We will deliver a second year of the **Autism in Schools Project** and do an evaluation of both years of the project.

Resource development

- We have made a sensory assessment tool for General Practices to make them more accessible for autistic people.
- We have made a training package for GPs to teach them how to work with autistic people.
- We have shared case studies showing how Personal Health Budgets can help autistic people leave hospital earlier.



Next steps: We will be making a tool for **Eating Disorder Units** to improve experience for autistic people.