

Plain English newsletter

Number 19, July 2025



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1. Who should read the newsletter

- People with a learning disability and autistic people with a learning disability
- families, carers, and advocates
- community groups, charities and advocacy groups who can explain to their members any difficult ideas and use these for information sessions

You may find some of the information in this newsletter upsetting, so please make sure you can talk to someone, if you need to.

We have included links to webpages so you can find out more.

2. Words we use

The newsletter is for people who have different needs and skills.

It can be difficult for some people to understand health services.

We try our best to use words that people know.

Hard words are in **bold** and **purple**. We explain the hard words.

If you don't understand any words, ask someone to explain them to you.

3. Mental Capacity Act guidance

There is a public organisation that looks at how safe patients are when they are using health services.

It looked at the care of people with a learning disability in hospitals.

They said that staff in hospitals did not always know how to tell if someone with a learning disability had **capacity** under the Mental Capacity Act.

Capacity means being able to make decisions for yourself.

We have written some advice (guidance) for staff in hospitals about capacity.

You can find the guidance on the NHS England website <u>NHS England »</u> <u>Guidance to support implementation of the Mental Capacity Act in acute trusts</u> for adults with a learning disability

We worked with people with lived experience, experts and staff in the NHS to write the guidance.

We made some tools to help doctors and nurses follow the Mental Capacity Act when they are caring for people.

What staff should do:

- staff in hospitals should use reasonable adjustments to help you understand information
- they should carefully check if you are able to make decisions about treatment you may have for your health condition

If you can't make a decision for yourself, they will involve your family or other people who know you.

Once health staff have talked to the people who know you best, they will make a decision in your **best interest**.

A **best interest decision** is where everyone involved in your health and wellbeing make the best decision together on your care and treatment.

It is important for you to know about the Mental Capacity Act.

For more information on the Mental Capacity Act for England visit <u>Mental</u> <u>Capacity Act 2005: what the law says about supporting people to make</u> <u>decisions about their lives</u>

4. Building better lives in the community

We know that helping people to build better lives in the community means reducing **restrictive practices** that are not needed.

Restraint can be described as making someone do something they don't want to do or stopping someone doing something they want to do.

Different types of restraint are called restrictive practices.

We are working with other health and care organisations to reduce restrictive practices for adults with a learning disability and autistic adults living in their own homes.

The work is looking at highly restrictive care and support in the community.

Highly restrictive care and support means more than 2 staff with a person at the same time.

People with a learning disability and autistic people say that having this many staff with them can be difficult.

It could be a form of restraint or restrictive practice.

We coproduced a plan with people with a learning disability and autistic people, their families, and other people in their care.

We have meetings called 'building better lives in the community network', 4 times a year.

We hear people's stories of how restrictions have been reduced.

You can find out more about the network by emailing <u>england.communitydevelopment@nhs.net</u> and how reducing restrictions may help you or your loved one.

5. Annual health checks

It is important that people with a learning disability have an **annual health check** and get a **health action plan** to help people live longer and healthier lives.

Annual health checks are once a year checks, for people with a learning disability who are on the **GP learning disability register** and are 14 years old or older.

The **GP learning disability register** is a list of people with a learning disability that the GP (doctor) practice looks after.

A health action plan should include:

- what your health goals are
- what your GP (doctor) is going to do
- what you are going to do to look after your health
- health action plans should be easy to understand and available on paper or digitally, for example being emailed to your phone

Best practice for annual health checks:

annual health checks should be at least 40 minutes long and be face to face

You may be seen by different health care professionals during your annual health check, which should include:

- checking your blood pressure, weight, height, measuring your waist
- talking to you about the health conditions you have and any medicines you take
- talking to you about your thoughts and feelings (mental health)

You can talk to your doctor or nurse about the kind of **reasonable adjustments** you need.

A **reasonable adjustment** is a change that a service can make, to help someone with a disability.

You can find out more about reasonable adjustments in newsletter 17.

To see what having an annual health check looks like, watch this video <u>Harshi's</u> learning disability annual health check and health action plan.

To see what having a health action plan looks like, watch this video <u>Charlotte's</u> <u>annual health check and health action plan</u>.

6. How to get support and speak up

If you are worried about the care and treatment the NHS is giving you, tell someone you trust straight away.

The NHS has made an easy-read form. It helps you tell staff or a service what you think could be done better.

Find the form by visiting <u>www.speakup.org.uk</u> and click on projects and search for 'Ask, Listen, Do'.

Ask someone to help you fill in the form if you need to.

7. People who can help you

An **Advocate** can help you to tell people what you need to try and get you the right health and social care support.

Find out more about advocates on the NHS website.

The NHS Patient Advice and Liaison Service (PALS) can support with healthcare queries or problems. If you are in hospital, you can ask staff how to contact PALS.

Or visit <u>What is PALS (Patient Advice and Liaison Service)? - NHS</u> to find out more and your nearest PALS office.

Your local Healthwatch can help with questions about your GP, hospitals, dentists, pharmacies, care homes or other support services.

To find out more about Healthwatch visit www.healthwatch.co.uk

If you are a parent carer, you can contact your <u>local parent carer forum</u>. Parent carer forums can help services in their area meet the needs of disabled children and young people and their families.

8. Keep updated

This newsletter was created by the NHS England learning disability and autism programme, with member representatives from our <u>advisory group</u>

Get in touch if you want to tell us anything about this newsletter.

You can either phone us on 0113 824 9686 or email us at engage@nhs.net

Update email

Sign up for our monthly learning disability and autism update email which includes important health information.

Already shared on our social media pages, the update email provides this all in one place.

To register to receive this, email us at engage@nhs.net

9. Connect with us

- Facebook: NHS England learning disability and autism programme
- X (was called Twitter): @NHSAbility
- Email: engage@nhs.net