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Julie wants to tell you about what NHS England is doing to make the NHS better for people with a learning disability.

1 Building the Right Support

This is a plan we have made for people with a learning disability and/or autism that also have a mental health issue or behaviour that is a challenge to services.

The plan will support people to get care in their communities. This will be at home, not in hospital.

We have set up transforming care partnerships. These include the NHS, councils and people with a learning disability and their families. Their aim is to bring care closer to people’s homes.
Care and treatment reviews help people with a learning disability to get the support and care they need.

Care and treatment reviews are for people with a learning disability who are in a specialist hospital, or might need to go in one.

A specialist hospital only gives care to people who have a certain illness.

Care and treatment reviews help people with a learning disability to get the support and care they need.

We are finding out why some people with a learning disability are dying too young. This is so we can stop people dying early.
It is important to have a health check because some illnesses do not get better without help. The sooner the doctor finds out, the easier it will be to make you better.

We are working to make sure everybody with a learning disability has an annual health check with their doctor.

It is important to have a health check because some illnesses do not get better without help. The sooner the doctor finds out, the easier it will be to make you better.

We want to stop people being given medications that they do not need. You can find out more about this on page 8.

A person with a learning disability can do more things and has more choices when they have a job.
NHS England is employing more people with a learning disability and helping the whole of the NHS to do the same.

Julie is looking forward to meeting self-advocacy groups and charities. They are very important because they speak for people and help the NHS and councils to make things better.

You can find out more about this at:

www.england.nhs.uk/learningdisabilities/resources/er/
We want to tell you what NHS England is doing to stop people with a learning disability being given medication they don’t need.

Sometimes people are given medication when they do not need it.

Usually people with mental health problems are given medication. An example of a mental health problem is when people hear voices or have ideas that are not real, but they make that person upset.

Medication can make people feel very tired, or not feel like themselves. It can also make people gain weight.
Other side effects can be a person’s organs not working or that person dying before they should.

Every day, around 30,000 to 35,000 adults with a learning disability are prescribed mental health medication without a good reason. This includes antipsychotic and antidepressant medication.

NHS England wants to stop people with a learning disability being given medication they don’t need.

- This means the person with a learning disability can get the care they need.
What is NHS England doing to make this happen?

NHS England has guidelines about prescribing medicine to people with a learning disability. It is for people who have challenging behaviour when they use a service.

NHS England has given doctors some information about people with a learning disability being given medication they don’t need. This is to try and stop it from happening.

• It will also make the quality of life of a person with a learning disability better.

• It will also help them to live longer, so they can spend more time with their family and friends.
NHS England has also held events with nurses and pharmacists. They will be talking about how to stop people with a learning disability being given medication they don’t need.

The Challenging Behaviour Foundation are doing some work to support family carers.

CHANGE are working with people who have a learning disability to find out about their experiences of using medication. They are also making easy read information to get people to think about whether they are taking medication they don’t need.

If you are worried about your medication - keep taking it and talk to your doctor.
Health Action Superheroes Comic
This is an extract of a comic book written by York self-advocates
HEATHER IS VISITING HER GP WITH HER SUPPORT WORKER

BUT THE DOCTOR ISN’T LISTENING.

SHE’S FINE.

WHY ISN’T HE LISTENING TO ME?

THAT’S OKAY THEN.

SHE WENT BACK TO SELF ADVOCATES HQ AND TOLD THEM WHAT HAPPENED.

HE DIDN’T LISTEN TO WHAT I HAD TO SAY!

HE JUST ASKED MY SUPPORT WORKER INSTEAD!

IT’S IMPORTANT THAT OUR DOCTORS UNDERSTAND OUR NEEDS.

THEN WE CAN BE SURE THEY WILL BE THE RIGHT DOCTOR FOR US.

MAYBE WE COULD GET INVOLVED WITH INTERVIEWING FOR A NEW DOCTOR.

TO BE CONTINUED...

Read more at:
www.yorkmind.org.uk/what-we-do/advocacy
An annual health check is a health check that happens once a year. People with a learning disability can have an annual health check.

The health check can take up to one hour. You can stop the health check at any time.
Sometimes, people with a learning disability might not know if they are unwell.

By having an annual health check, people with a learning disability can get treatment which will make them feel better.

Sometimes, serious illnesses can be found earlier and treated earlier.

If you are aged 14 or older, your doctor should ask you to come for an annual health check.
When you are having an annual health check, your doctor or nurse will:

- Check your weight, heart rate and blood pressure.

- Take blood and wee samples.
If you have any illnesses like diabetes or asthma, they will ask how you are coping with them.

They will also ask questions about your mental health and how you live your life.

They will also check any medicines that you take.
They will also look at any support you get from other health professionals. An example of health professionals would be physiotherapists or speech therapists.

If you are nearly 18 you might talk about any other support you might need.

If you have any other health problems because of a disability, you might have to do more tests. An example of this is, if you have Down’s Syndrome, you might have to do a thyroid test.
5 Will I understand my annual health check?

Your doctor can give you more time for an appointment if you need it.

They can also use pictures, large print, and plain English so you can understand your annual health check.

6 How many people have an annual health check?

Less than half of people with a learning disability have an annual health check.

We want more people with a learning disability to have an annual health check. Ask your doctor about them.
What are groups in the NHS England forum doing?

Grapevine is an organisation in Warwickshire that has been using roleplay to train people with a learning disability. This is to tell people about annual health checks and health passports.

A health passport helps people with autism get the care they need from doctors, nurses and other healthcare professionals.

People said they enjoyed the sessions and learnt about how to get an annual health check and a health passport.

People First are an organisation in Merseyside who have played a “Guess Who” game to help people understand how health passports are used.
Too many people with a learning disability and/or autism are spending too long in assessment and treatment units.

This is because there is not enough support or services in their local communities.

People who work for the NHS and local councils are working together to make support better in the community. These groups are called transforming care partnerships.

People First have also used videos and roleplay to help people understand what happens when they have an annual health check.
The 48 transforming care partnerships will work with people who have a learning disability, their families, carers and the people that support them.

They will decide what services are needed in their area so that less people need to stay in hospital.

Each area has made a plan that says what is needed to make sure the right services are available to support people to live at home and in their community.
The plans look at things like:

- how different areas can make sure people and their families plan their own care. An example of this would be using a personal health budget

- how different areas can help people and their families understand the support they can get and the choices they have

- what kind of local housing is needed to meet people’s needs
NHS England want you to get involved in the work of the transforming care partnerships. To find out more about the transforming care partnerships in your area, go to:

www.england.nhs.uk/learningdisabilities/tcp/contact

• the kind of training that carers and support workers might need

• the need for free independent support and advice
In January 2016 NHS England asked self-advocacy groups to apply for grants.

The grants were for projects that helped people to work with NHS England to learn about what it does. It was important that the people involved were those who NHS England doesn’t normally hear from.

NHS England gave out six grants to different groups. The projects that we funded are:

People First Merseyside held an event called “Passports to good health”. It was about what annual health checks and health passports are and how people can get them.
Support for Living are doing some work around transforming care partnerships in North West London. They are looking at good health support for people with a learning disability who have challenging behaviour when they use health services.

Dorset People First talked to people in small villages about the Accessible Information Standard.

They used maps to find out the journeys that people take through the NHS. They also looked at whether the information people got on their journey was easy to understand.
Changing Our Lives spoke to young people with profound learning disabilities about mental health. They wanted to find out how mental health services can be made more accessible for people with a learning disability. They used poetry and graffiti to express their thoughts and ideas.

Gateshead People are talking to people who don’t get support from paid staff, family or carers. They are asking people about their experience and awareness of annual health checks and how they can be made better.
CHANGE are talking to people who have used, or are using, antipsychotic medication. They will have an event where people can share their experiences as well as making an easy read guide for people with learning disabilities.

Get involved

NHS England's learning disability advisory group are recruiting for 12 people to be on our advisory group.

The advisory group will offer support and guidance to NHS England on its work around learning disability. You will have to attend three meetings a year. Please email: ldengage@nhs.net for an information pack.
Fortnightly bulletin

If you would like email updates about what NHS England is doing for people with a learning disability, please let us know.

Watch our weekly video blogs

We interview someone working in the learning disability programme every week. See the videos on our YouTube channel.

Talk to us on social media:

Facebook:
NHS England Learning Disability (closed group)

Twitter: @LDEngagement

Youtube:
www.youtube.com/user/TheNHSEngland
Spot the difference

Make note of any differences you spot here:
Contact NHS England

NHS England’s Learning Disability Engagement team

Telephone: 0113 824 9686

Email: ldengage@nhs.net

Facebook: NHS England Learning Disability Engagement (closed group)

Twitter: @LDEngagement

If you would like a hard copy or would like to receive future editions of the newsletter, you can email CHANGE at: info@changepeople.org