



Easy Read Newsletter



**Better support
for children and
young people**

**Sharing health
information**

Ask Listen Do

And lots more...

Summer 2018

Hello

Welcome to our summer newsletter

It is for people with a **learning disability**
and **autistic** people

In this newsletter we just say **people**



Summer 2018



Hello from NHS England.

We plan and pay for health services in England.



We want everyone to have good health and good care.



There is lots of information in this issue. We have tried to make it easy to read.



Sometimes you will see [blue web links](#) and emails to find out more. You can click these on the computer.



It's always good to hear what our readers think. So please get in touch if you have any ideas to make this newsletter better.



We would love to hear from you.

Our email is engage@nhs.net

In this issue...



We've been busy working since the last issue and would like to tell you about it.

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Support for young people



Recently we have been doing some work for young people who have problems with **mental health** or **behaviour that challenges** families and services.

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Stopping over medication



Too many people are given medicine without knowing if it will make them better.

STOMP is a campaign to stop this.



Ask Listen Do is our project to help health, education and social care services to be better at listening to people.



Soon there will be a new way to make sure every part of the NHS knows how you like to be treated.



Can you spot the difference between the two pictures? - see if you can find all ten.



A message from Ray James
the Director of Learning Disabilities
at NHS England.

The right support for children and young people



NHS England work with children and young people as well as adults.



Recently we have been doing some work for young people who have problems with **mental health** or **behaviour that challenges** families and services.

We know too many people are spending a lot of time in hospital because they cannot get the support they need near home.





We think everyone should get good support in their own home as much as possible.



TCPs

To look into this we are working with groups across England called **Transforming Care Partnerships**.

We call them **TCPs** for short. Everyone works together – NHS and council staff, people and families.



They have meetings, share ideas and make plans for their local area.



NHS England made a list of 9 things we think make a good life for young people. We sent this list to all the TCPs so they can check how things are in their part of the country.

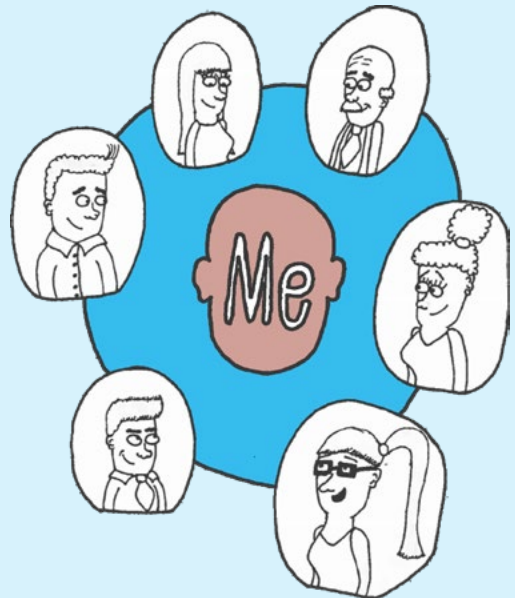


1.

Children and young people should get the chance to do things they enjoy - like go to school or work, have friends and try new things.

2.

People need well planned care and support that gives them the help they need.



3.

People should get to choose their own care.



4.

Families must get the right help as well - because sometimes people stay in hospital if their families or carers cannot get support.

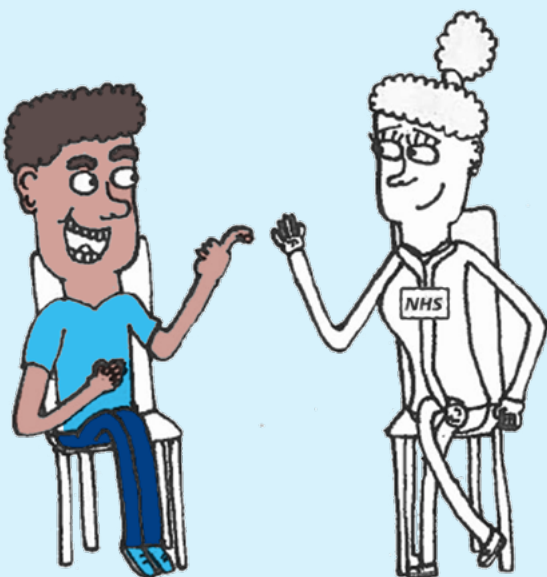
5.

Children and young people should choose where they live - and who they want to live with.



6.

People should get good care from health services.



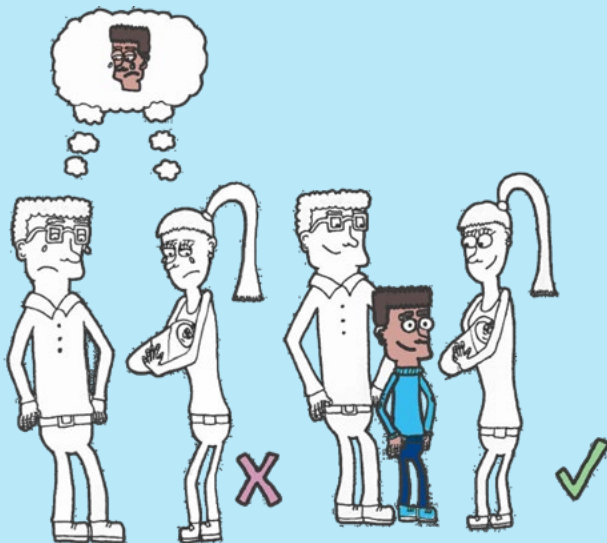


7.

People should get the extra health and social care they need near where they live, not far away.

8.

Some people might need help to stay out of trouble with the law.



9.

If there is no other choice but hospital, people should go home as soon as possible.



Children need good support starting from a very young age.



They should get all the help they need to stay in their local school.



Transforming Care Partnerships should work with local children, young people and their families to make sure these things are happening.



Find out more...



If you want to get in touch there are NHS England staff in each part of the country working with children and young people :



South

Cindy Gordillo

c.gordillo@nhs.net



London

Maureen Banda

maureen.banda@nhs.net



North

Siobhan Gorry

siobhan.gorry@nhs.net



Midlands and East

Kate Sutton

kate.sutton1@nhs.net

STOMP

Stopping over medication



If you have depression, anxiety, problems sleeping or epilepsy you might be given medicine to help you get better.



This might be a **psychotropic medicine** which can affect your mind, emotion and behaviour.



These medicines can make you feel poorly if you take them for too long, or take too many. You might :



- put on weight
- feel tired or 'drugged'
- start feeling ill



Sometimes people are given medication when they are not ill but because their behaviour is seen as challenging. This is wrong.

STOMP

Stopping over medication



We support

STOMP

About 35,000 people in England are given medicine without knowing if it will help them get better.

STOMP is a **campaign** – Stop The Over Medication of People with a learning disability, autism or both.



It is about making sure people get the right medicine – as long as they need it.



Important!

Your medicine may be right for you – you might need to take it to stay well.



Keep taking your medicine- stopping could be dangerous.



Speak to the person who writes your prescription – maybe your **doctor**, **pharmacist** or **psychiatrist**.



Ask for a **medication review**, which is a kind of check-up.



You can always ask for help from someone you trust or an **advocate**.

Help us STOMP out over medication!

Watch this MixIT video bit.ly/stomp-mixit



Read this easy read leaflet

bit.ly/stomp-leaflet



Tell your health and social care services about this website

bit.ly/stomp-resources

Ask Listen Do



We think services should :

1. **Ask** what you think
2. **Listen** to what you say
3. **Do** something about it



Ask Listen Do is a project to help health, education and social care be better at listening to people. We are looking at :



Feedback - when staff ask you what you think about something - like if your care was good or bad?



Concerns - when you are worried or unhappy about something but it can be sorted out straightaway.



Complaints - if you are really unhappy you can make a complaint. Someone will find out more and then tell you what they will do to put things right.



Sometimes it is easier to write your complaint in a letter. You can always ask someone to help you with this.



If you are still unhappy you have rights to take this further.



Ask Listen Do wanted to find out how things are for people.

We made an easy read survey and had some events to share ideas.



Now we are working on new **guidance** and training for staff. We will have more events in the future.





You can complain about services NHS England pays for

Phone **0300 311 22 33**

Email england.contactus@nhs.net



We pay for things like GPs, dentists, opticians, pharmacies and health services in prison.



Find out more

You can read what people have said so far on our website :

bit.ly/ask-listen-do



Find out more about the Ask Listen Do project :

<http://bit.ly/ask-listen-do-main>

Sharing information about your support needs



Everyone has different support needs. Soon there will be a new way to make sure every part of the NHS knows how you like to be treated.



You will be able to ask your **GP** (your doctor) to put a note on the computer about the kind of support you like. We call this note a **flag**.



Tell your GP what you want written in your flag. Things like :



Easy read



Extra time



Speak slowly

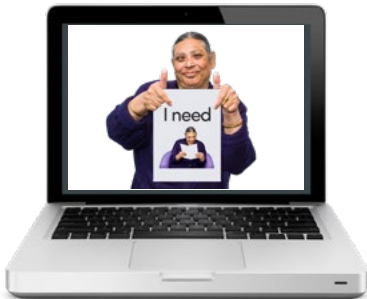


Whenever you use any NHS service the staff can read this flag - and know how best to look after you.

Sharing information about your support needs



We had an event to find out what people think. These are people's ideas from the day :



People thought it would be good to share information about these things :



How to **communicate** with you



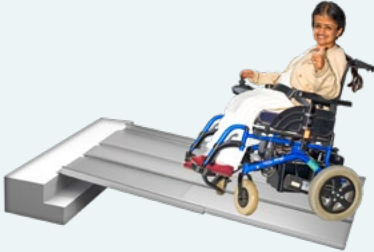
Who to **involve** in your healthcare



Things that help with your **treatment**



Which doctor or nurse you prefer



Any physical or **access** needs



How you like your **appointments** to be
- things like afternoons only
or a reminder on the day.



A reminder about being friendly and welcoming.



What you **can** do for yourself
(not just what you can't do)



Sharing information about your support needs



We talked about which staff should see the information :



It would be good if healthcare staff know about your support needs before they meet you.



It is good for **receptionists** to know about your support needs but they don't need to know about your healthcare.



This is really good for people with a learning disability, autism and for other disabled people.



This would be great for children from a young age.



We talked about things that worry us :



Everyone is different. You should choose what information to share.



The flag is only useful if staff read the information.



Staff need training- to know about learning disability and autism.



You know best about your support needs - more than health staff.



Keep my information safe - only people who should read it should get it.

Sharing information about your support needs

Things you can do



Mencap have made a letter you can print out and take to your GP :

bit.ly/gp-letter



Read some more information here :

bit.ly/nhs-flag-event



Watch this video :

bit.ly/NHS-flag-sharing



Summer puzzle

Can you spot the difference between the two photos?
Try and find all ten!



Thank you from Ray James



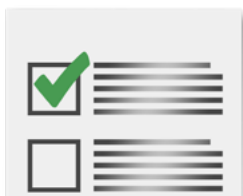
Thank you for reading this newsletter.
My name is Ray. I am the new Learning Disability Director at NHS England.



Before, I worked in health, housing and social care in London.



Now I have joined NHS England to make services better for people and their families and carers.



Here are some of the things I want to do:



Make real changes that make people's lives better



Make things better for families and carers



Have better care in the community
for people who need more support



Make sure services listen to you



Make sure every part of the NHS
supports people in a good way



Have more support near where
people live so they don't have to
stay in hospitals



I think it's important that we listen to
you when we are making plans for NHS
England.



I would love to hear from you :
england.learning.disability@nhs.net

The last word

From Dudley Voices for Choice



That's the end of our summer newsletter. We hope you enjoyed reading it.



We give the last word to members of **Dudley Voices for Choice** – who told us what they think about the things in this newsletter.



If you want to tell us about something that's important to you – please phone or email.

Thank you to **Dudley Voices for Choice** for checking this newsletter is easy to read.

Made with Photosymbols® for NHS England.

Doctors and health staff should know us well - and we should know them well

Everybody should be treated with respect

We should be teaching doctors and nurses how to deal with other people with learning disabilities

When somebody isn't treated with respect, it could be me, you or somebody we know

Health staff should know about autism

My medical information should work abroad just in case I get ill when I'm away on holiday

Phone calls to GPs can be hard with all the 'press this button now' stuff



Contact us



The NHS England
Learning Disability and Autism
Engagement Team

Phone : [0113 824 9686](tel:01138249686)

Email : engage@nhs.net

Web : [www.england.nhs.uk/
learning-disabilities/about/get-
involved/forum](http://www.england.nhs.uk/learning-disabilities/about/get-involved/forum)

Facebook :
[NHS England Learning Disability
and Autism Engagement](https://www.facebook.com/NHSEnglandLearningDisabilityandAutismEngagement)

Twitter : [@NHSAbility](https://twitter.com/NHSAbility)

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