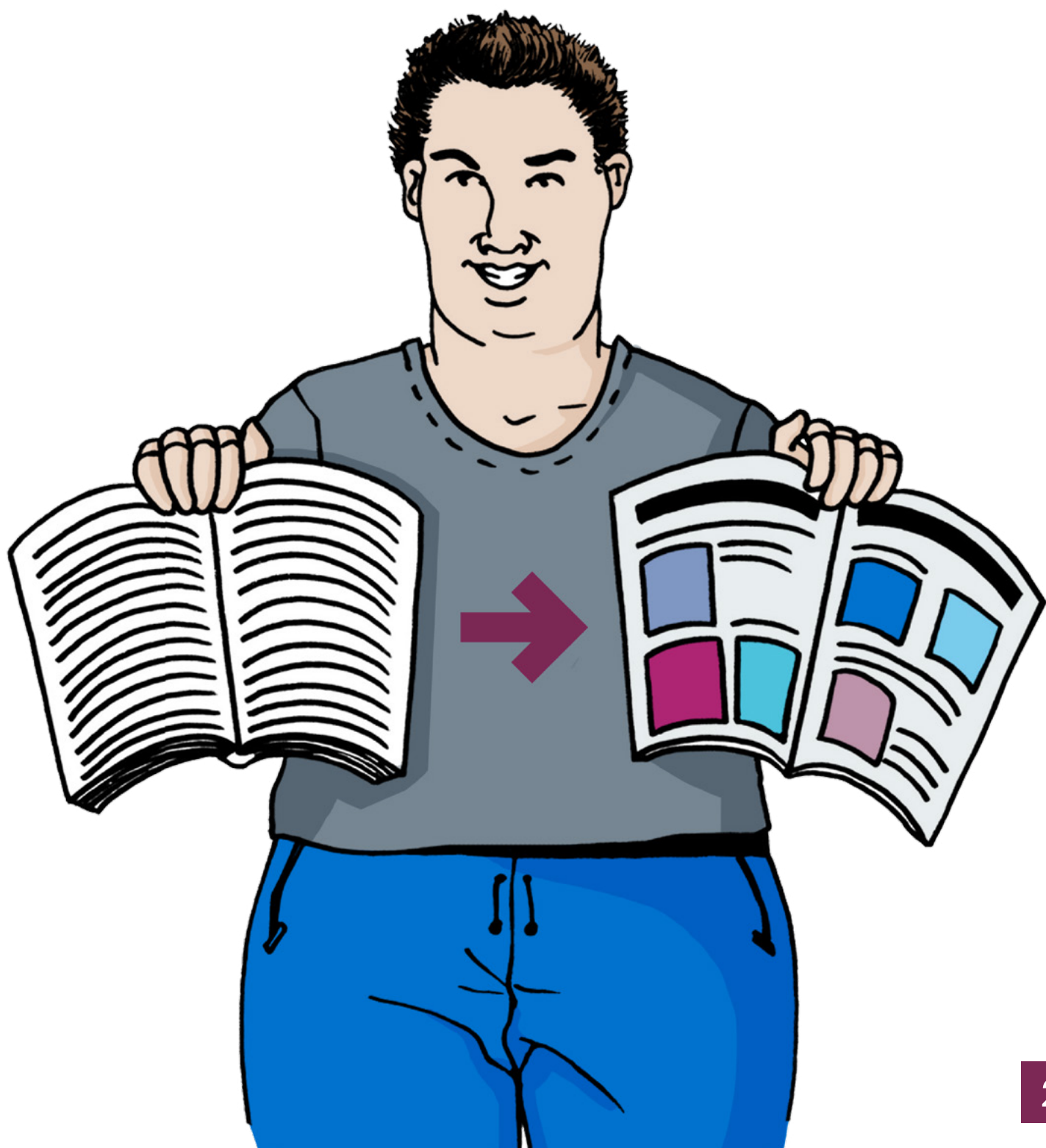


# The Learning Disability Newsletter

*Easy read*



**Summer 2017**



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# New National Clinical Director at NHS England



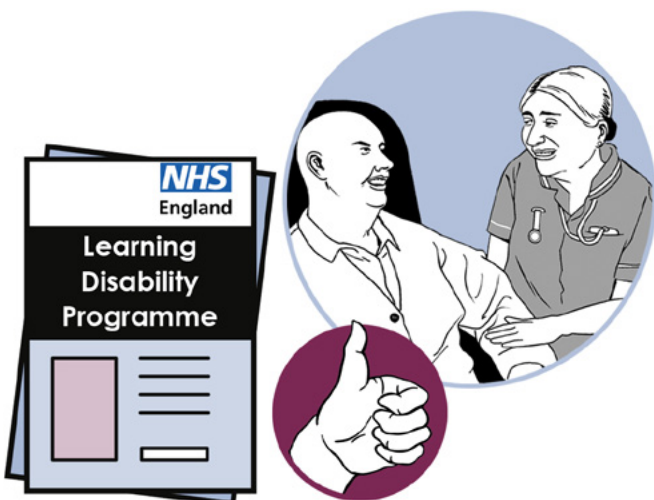
Jean O'Hara is the new National Clinical Director for learning disabilities at NHS England.

She is a psychiatrist for people with a learning disability.

She helps with mental health problems.



This means she brings the view of a doctor and a psychiatrist to the leadership at NHS England.



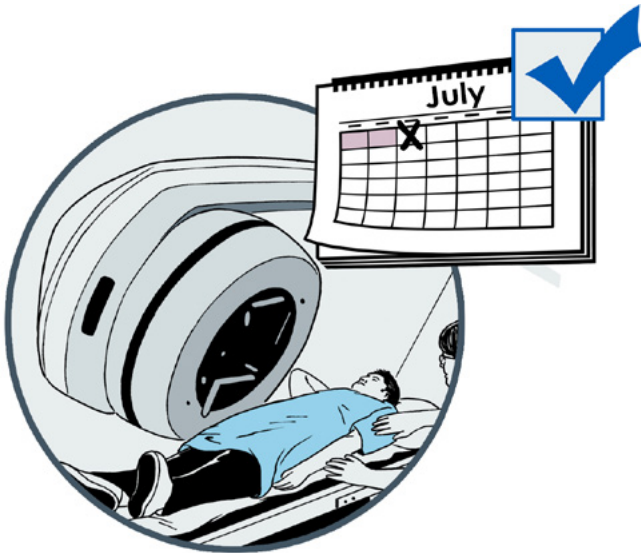
Jean is working on NHS England's Learning Disability Programme and with other organisations to improve care for people with a learning disability, autism or both.



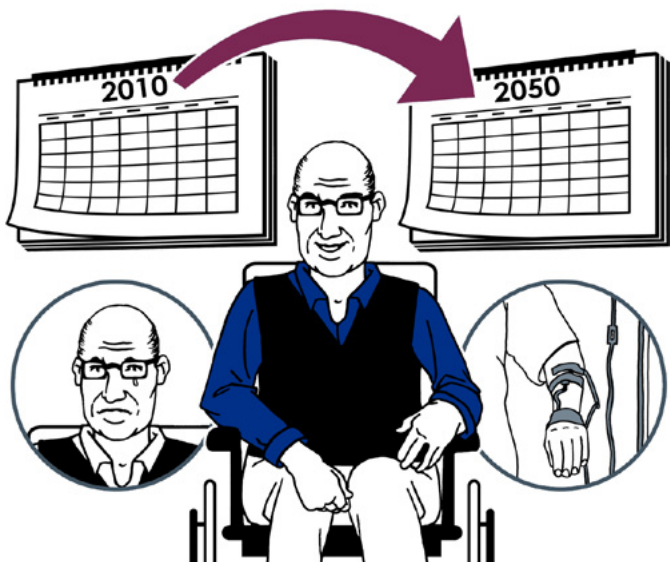
Jean is passionate about improving the health of people with a learning disability, autism or both.

She wants to:

- Speed up diagnosis and treatment

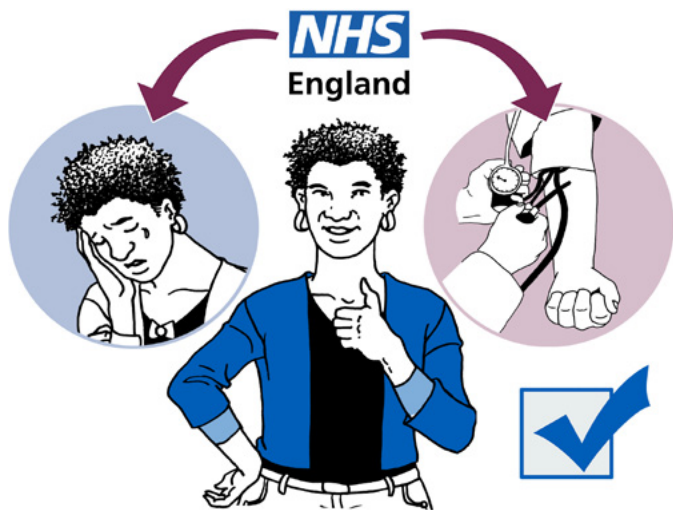


- Stop people dying early from things that could be prevented



People often have long term conditions which affect both their physical health and their mental health.





Jean wants the NHS to look at the whole person – both their mental and physical health.

This will improve people's health and wellbeing.



She wants people to be active and involved in their communities.



Jean wants medical students to get more experience of working with people with a learning disability, autism, or both, to help improve care.



You can share your thoughts with Jean by emailing [england.learning.disability@nhs.net](mailto:england.learning.disability@nhs.net)

# Care, education and treatment reviews for children and young people



Care and treatment reviews (CTRs) are meetings to plan support for people with a learning disability, autism or both:

- whose behaviour can be challenging and
- when there is a risk they may be admitted to, or have been admitted, to a specialist hospital.



There has been lots of feedback saying that NHS England's care and treatment review policy needed more information about how reviews should work for children and young people.



The policy has been updated and now has a section all about children and young people.



Education is a very important part of children's lives.



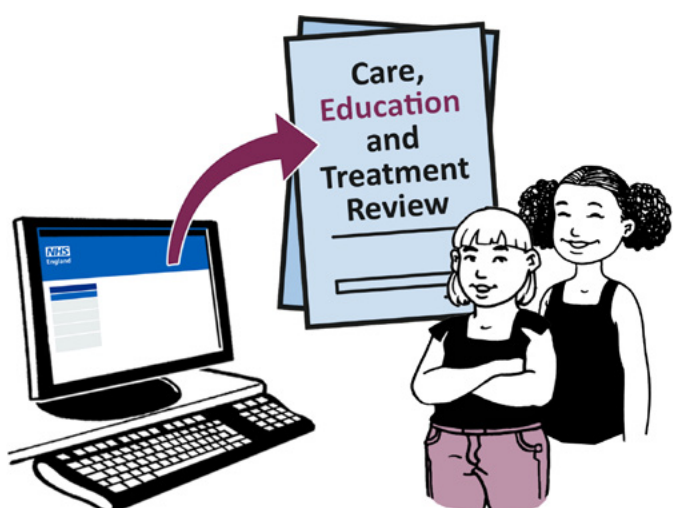
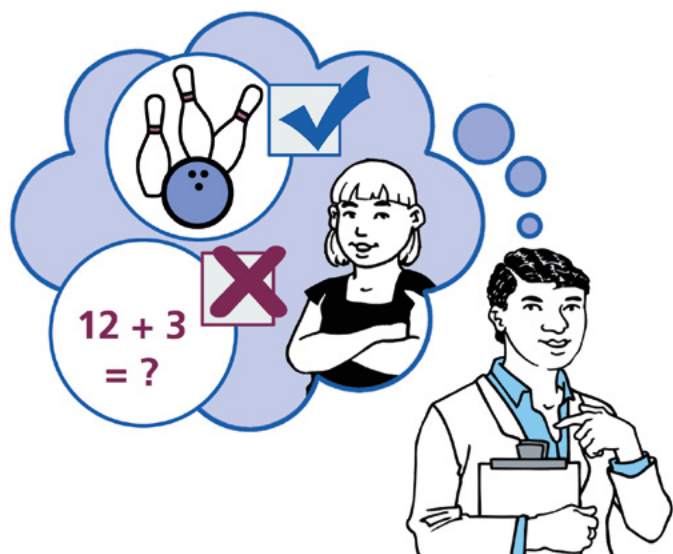
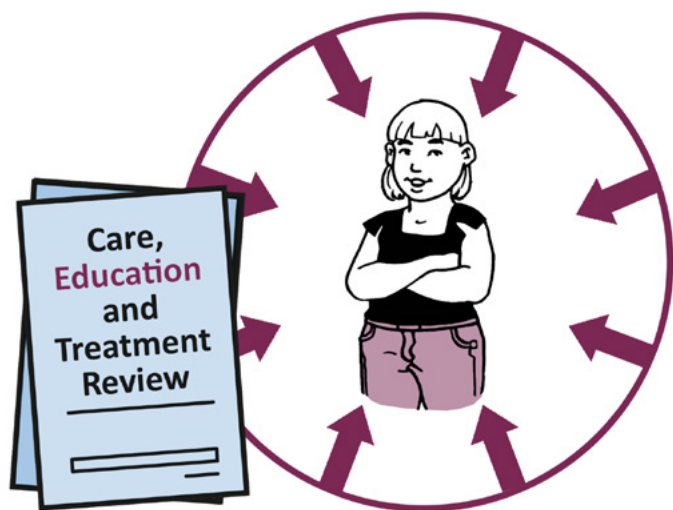
Care and treatment reviews for children and young people are now called care, education and treatment reviews (CETRs).

This is because reviews need to make sure education is an important part of planning.



There is information about who should make decisions for children and when young people should begin to make decisions for themselves.





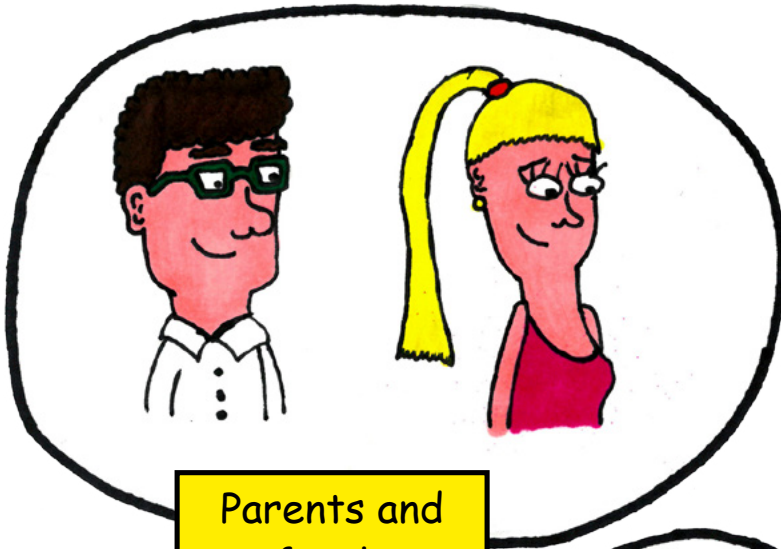
The document has person-centred questions to gather information about the child or young person for their review.

Some of these questions are what we like about them, what they are good at, and what they find difficult.

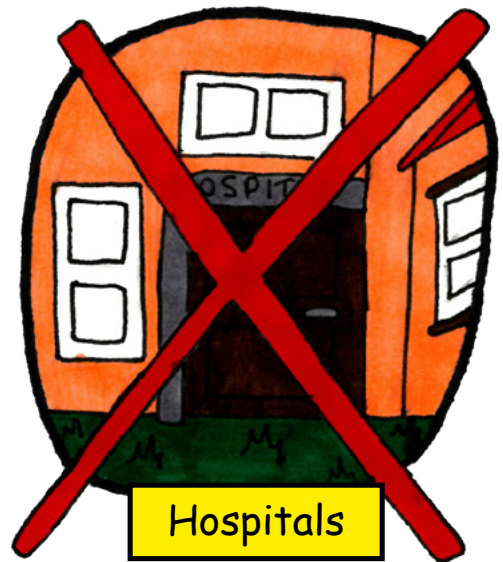
This helps everyone at the review think about the child or young person as an individual.

You can read the CTR policy here: <http://bit.ly/2r5oeM4>

Here is more information about care, education and treatment reviews for people who are involved in a review : <http://bit.ly/2po0GEO>



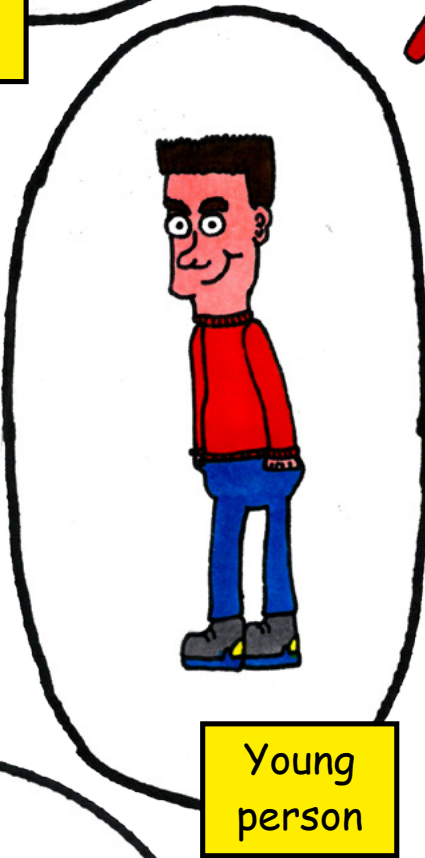
Parents and family



Hospitals



Education



Young person



Home



Professionals

## Care, Education and Treatment Reviews

David Gill

# Improving support for people who have difficulty swallowing

**NHS**  
England



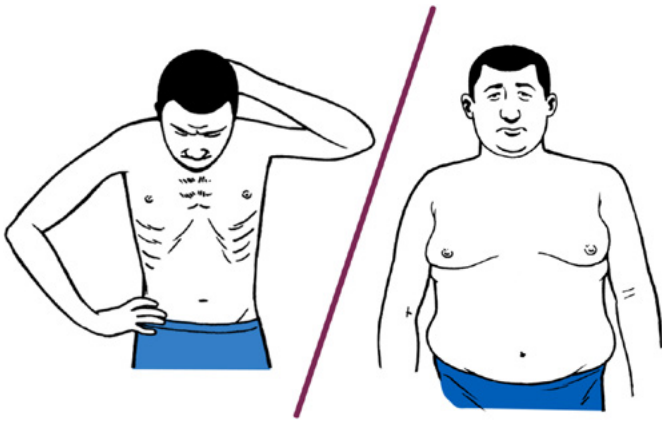
NHS England is doing work to help people who have difficulties in eating, drinking or swallowing.

This is called dysphagia.

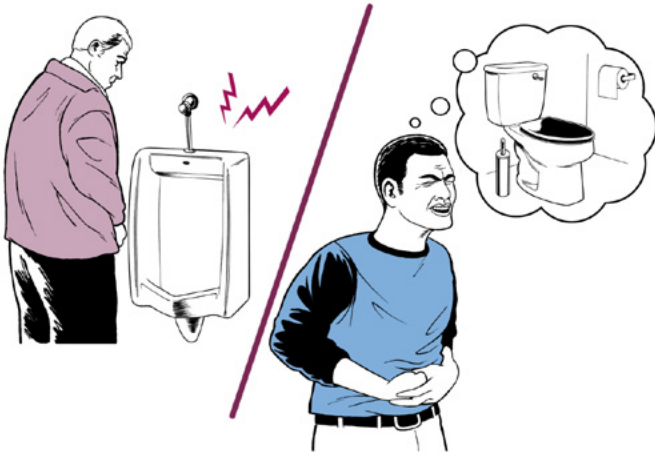
If you have dysphagia you are more likely to have problems with:

- Choking
- Infections of the food pipe or lungs
- Dehydration (not having enough fluid in your body)





- Malnutrition (not getting a good diet)



- Constipation and urinary infections (difficulty pooing or problems when you wee)



- Headaches



People may also feel left out because they have to eat different foods to other people.





People with a learning disability are more likely to have dysphagia, especially people with more severe or profound learning disabilities.



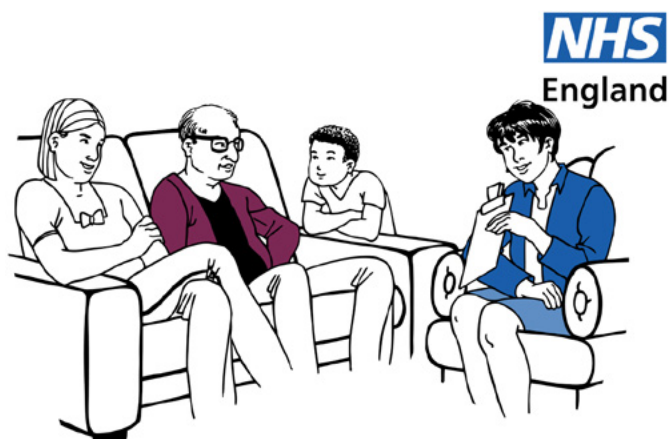
Some people may not understand dysphagia and may have it without knowing.

This means they will not get the support they need.



NHS England wants to find out why dysphagia is leading to some people dying early by talking to:

- People affected by dysphagia, and their families and carers





- Health staff who support people with dysphagia



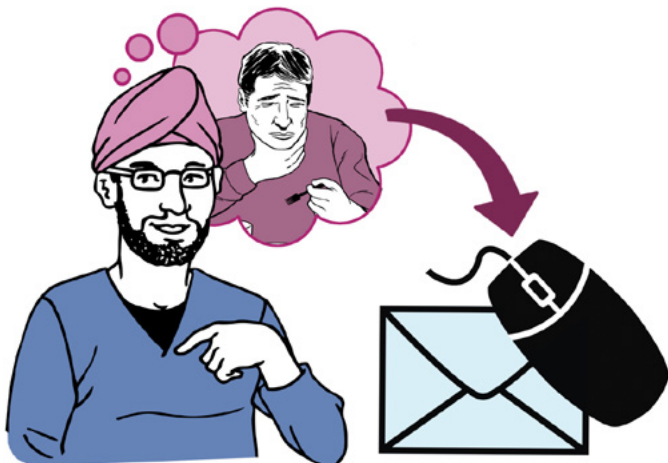
- Organisations supporting people with dysphagia



These are some of the things NHS England wants to understand:



- Are people with dysphagia and their families getting support from the right health staff?



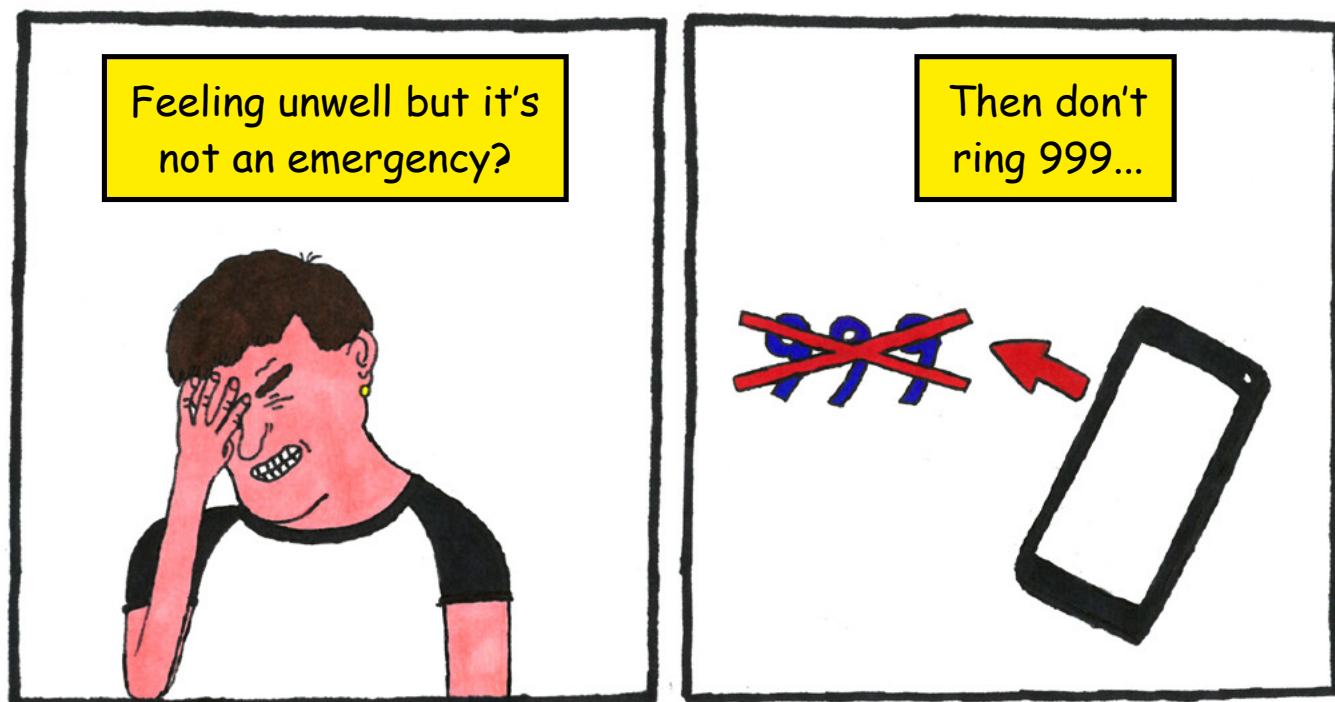
- If people have other health problems as well as dysphagia, do they have a person who makes sure they have all the support they need?

- Are people and their families getting training on dysphagia, and do they know how to support someone at mealtimes?

- Do people know about important things such as good posture and clean healthy teeth?

If you can help with these questions please contact Jane Kachika who is leading this work at [jane.kachika@nhs.net](mailto:jane.kachika@nhs.net)





when it's less  
urgent than 999

## NHS 111: An Inclusive Service

For more information the video is on the  
NHS England youtube page now

<http://bit.ly/2rjExHH>

David Gill



## *An event about making it easier to give complaints, comments and feedback*



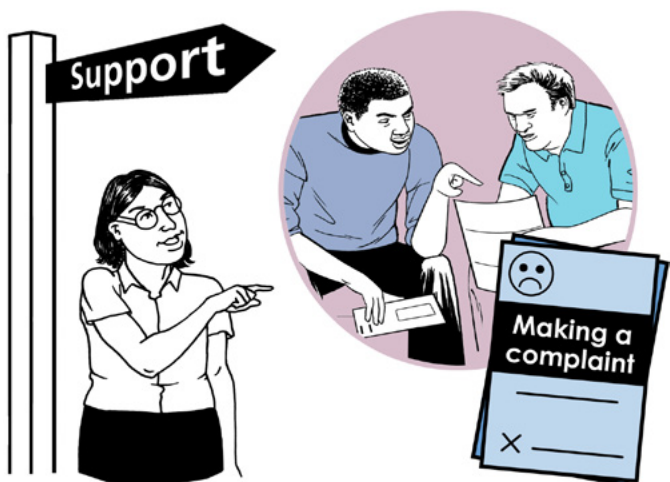
Thank you to people who came to the NHS England Learning Disability and Autism Forum event in March 2017.

The event was about improving the way that health and social care gets comments and complaints from people with a learning disability, autism or both.

When we say people we mean children, young people and adults.

People shared their experiences of giving feedback and making complaints and their ideas for making it better.





Here are some examples of what we heard:

- People need to know they have a right to complain and how to make a complaint.
- Making a complaint and giving feedback needs to be easier.
- Different ways to feedback or complain work for different people.

There should be well signposted, free, independent support to help people make a complaint, for example advocacy services.



Photos can be useful:  
People can take photos  
to describe what they are  
complaining about.

It can be useful to see a  
photo of the person you are  
complaining to.



It can be scary to make a  
complaint, especially if someone  
is in a locked hospital like an  
assessment and treatment unit.

It is important to make sure  
people who complain, and their  
loved ones, are safe.

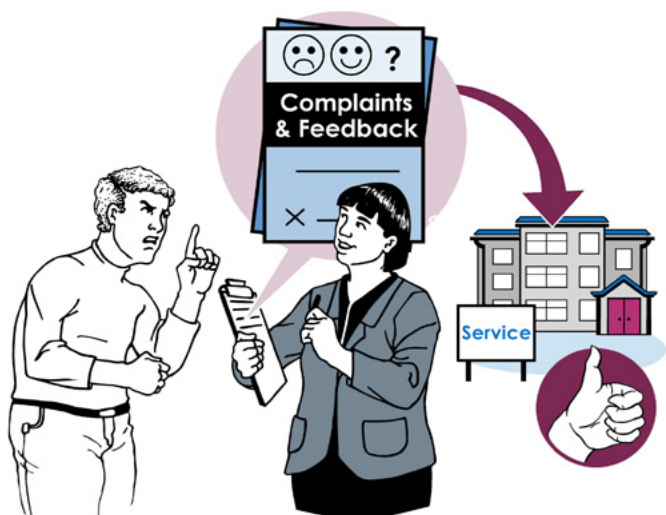


The organisation should stay  
in touch with the person who  
has complained to them using  
the way which the person  
complaining understands.  
For example easy read.





Staff should be trained to help you give feedback or make a complaint.



Organisations should welcome feedback and complaints to make their services better.

This could be NHS organisations or your care provider.



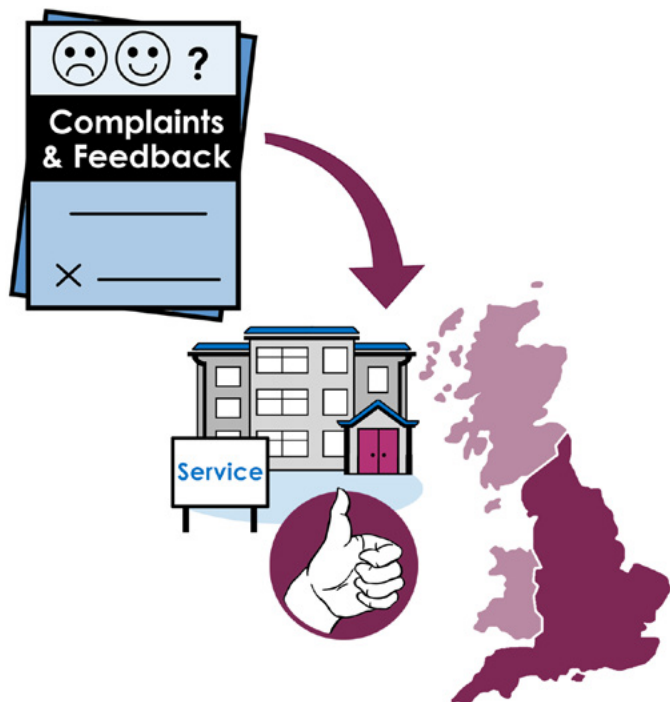
Organisations should make sure the person complaining understands the result of their complaint.





If you are not happy with the decision about the complaint you made, you need to know how to challenge the decision.

This is called an appeal.



Complaints and feedback should lead to improvements at that service and across the country.



**2 years**

### Next steps

The things people said at the event will help NHS England to make it better for people to make comments and complaints about health and social care.

This is part of a 2 year project.



This project will help people know that they have the right to complain and know how to complain.



It will also help organisations act on complaints and comments.



We will tell you more about the complaints work as it develops.

When we have written the event report it will be here:

<http://bit.ly/2slxteu>

# Guidance to help commissioners plan services



In July 2016 there was another NHS England Learning Disability and Autism Forum event.



We asked the Forum to help write guidance for commissioners.

Commissioners are people who plan and pay for services.

The guidance is about what makes good services for people whose behaviour can be most challenging.



It is for when someone cannot be safely supported in the community and hospital is the only safe option.





There are 3 kinds of service:

- Extra community support for people who have behaviour that is challenging.

This will help people to stay in the community.

This is called Enhanced or Intensive Support.



- Extra support in the community for people who have been or might get in trouble with the police.

This is called Community Forensic Support.



- Inpatient services for people with learning disability, autism or both, if no community treatment options work.

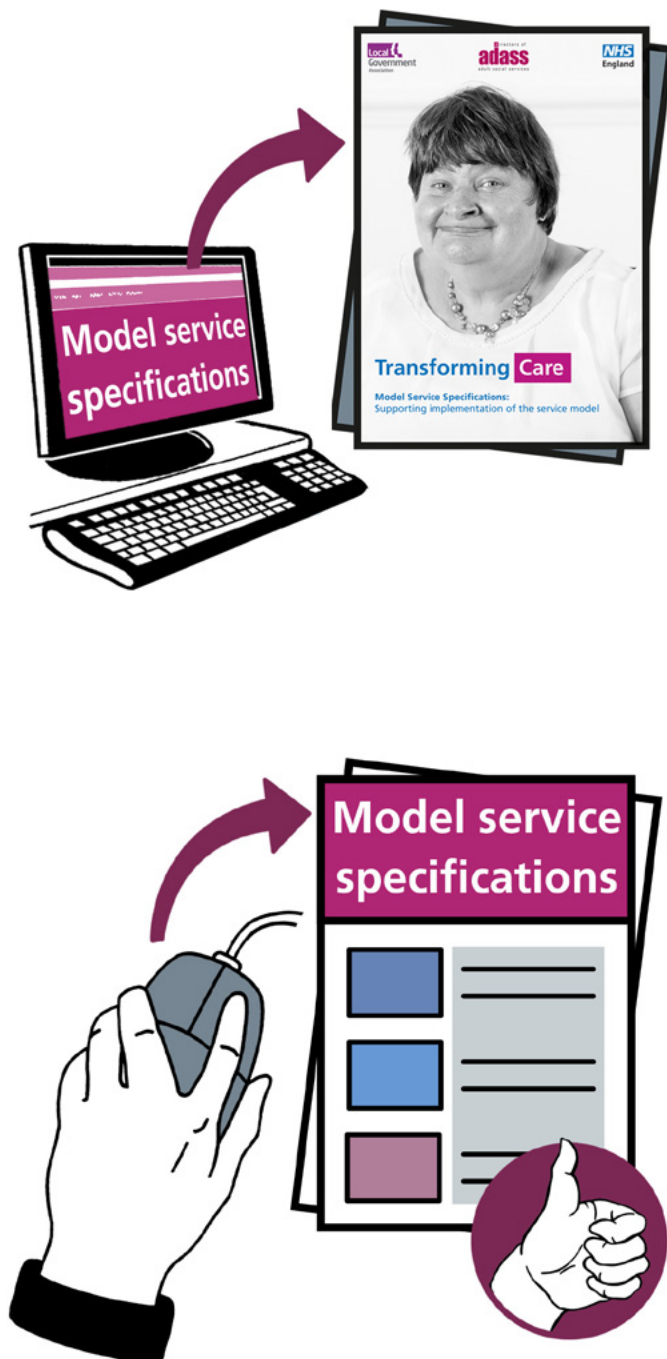


This guidance has now been published. It is called the 'Model Service Specifications'. It includes changes the Forum suggested.

You can read the guidance here:  
<http://bit.ly/2pXPwph>

And in easy read:  
<http://bit.ly/2qVL0oM>

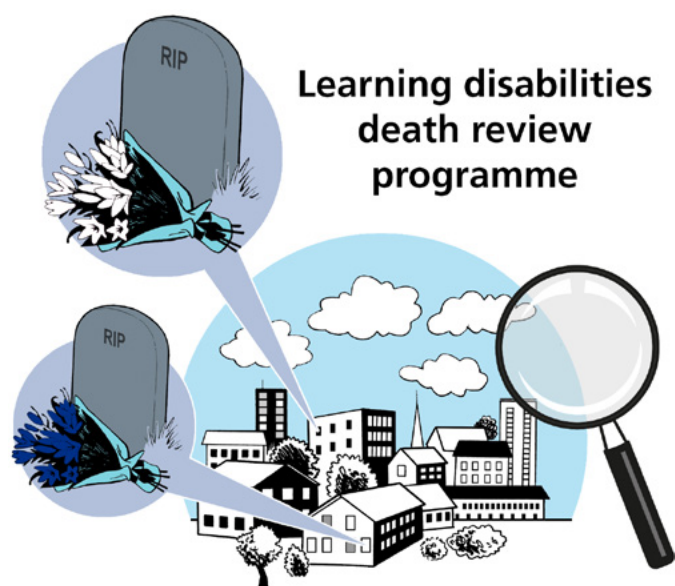
Thank you to everyone who shared ideas.



# Learning disabilities death reviews



Reports show that people with a learning disability sometimes die younger than other people.



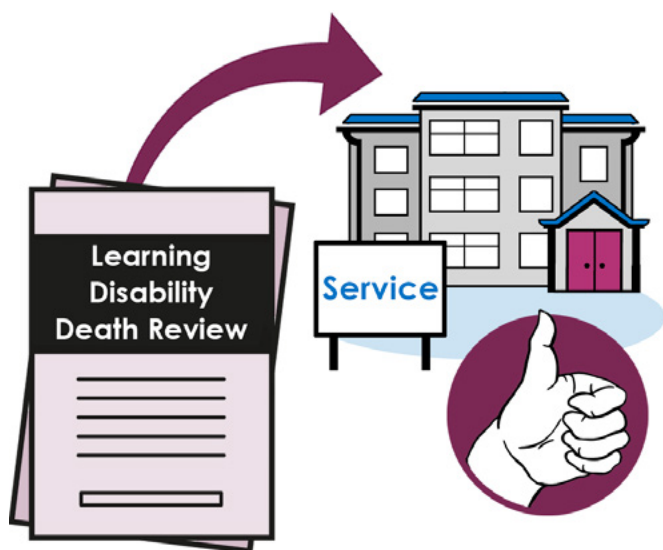
NHS England has asked a team to help local areas look at the deaths of people with a learning disability.

The team is called the LeDeR programme which stands for learning disabilities death review.



We are finding out why some people might be dying sooner than they should.





We are then helping to make services better so they can support people to live longer healthier lives.



Anyone with a learning disability aged 4 years and over will have a review of their death.

This is because it is hard to know if young children have a learning disability.



The review will include the views of the people who knew them best.

It will look at what worked well in supporting the person, and what could have been better.



An action plan will be used to make things better for other people with a learning disability if needed.

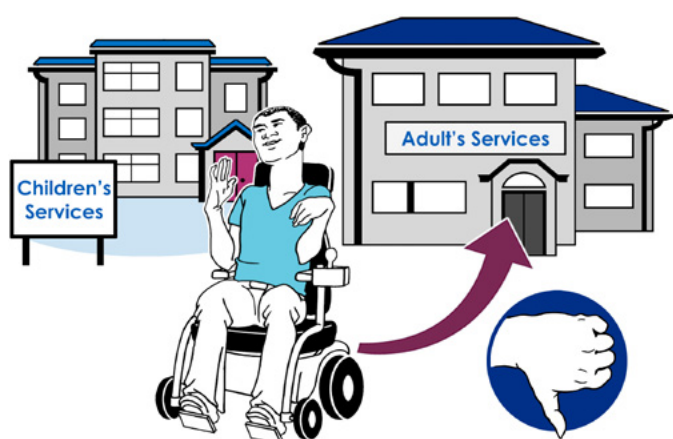
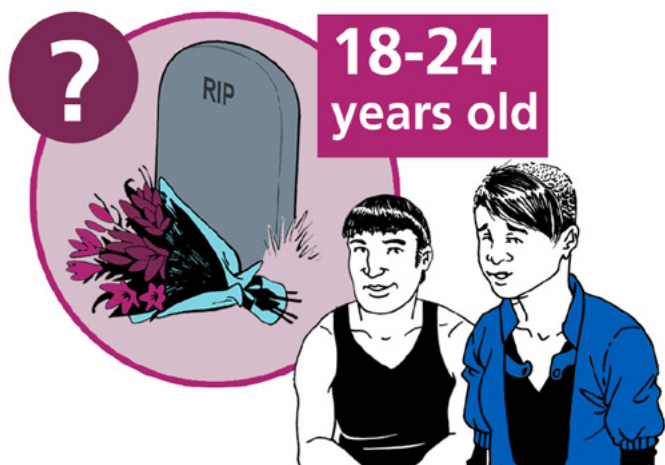


People with a learning disability have been helping the LeDeR team with the work.

There is an Advisory Group of people with a learning disability.



The LeDeR team is talking with self-advocacy groups about looking at the deaths of some people in more detail.



These are:

1. Deaths of people with a learning disability who were aged 18-24 when they died.

This is because they may have had problems moving from children's to adult's services.

2. Deaths of people with a learning disability from a black and minority ethnic community.

This is because we don't know enough about why they die.

If you have any ideas about the work, or want any more information, you can contact Pauline at

[leder-team@bristol.ac.uk](mailto:leder-team@bristol.ac.uk)

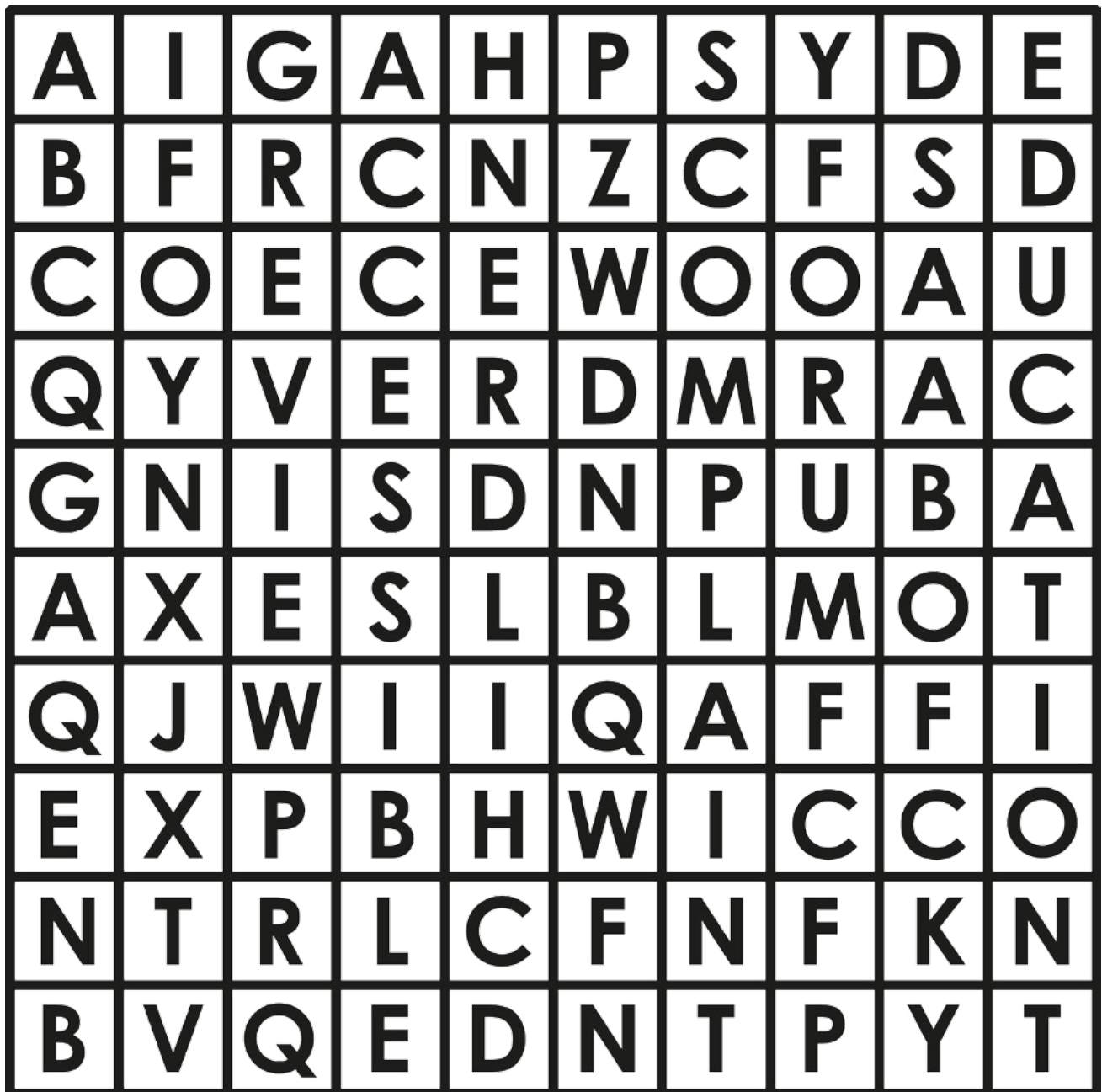




## Word search

Try and find these words in the word search below:

accessible, complaint, children, dysphagia, education, feedback,  
forum, review



Use this space to make any notes about what you have read in this newsletter:



**NHS**  
England



**NHS England's Learning  
Disability and Autism  
Engagement Team**

**Telephone:** 0113 824 9686

**Email:** [learningdisabilityautismengage@nhs.net](mailto:learningdisabilityautismengage@nhs.net)

**Facebook:** NHS England  
Learning Disability and Autism  
Engagement (closed group)

**Twitter:** @NHSEngage

If you contact us about any of these articles we will not share your personal details outside of NHS England.

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[learningdisabilityautismengage@nhs.net](mailto:learningdisabilityautismengage@nhs.net)