

The Learning Disability Update

Easy read



Autumn 2016



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An introduction by Simon Stevens

Chief Executive of NHS England



Welcome. This is the second learning disability update.



The health of people with a learning disability is one of our main priorities.



This is because there are lots of people with a learning disability in England that have poorer health than others.

I want to change this.



The best way of getting care right is for services to listen to what people with a learning disability want.

This includes doctors, dentists and hospitals as well as specialist services for people with a learning disability.

People with a learning disability have lots of skills and experiences that the NHS needs.

That is why we promise to employ more people with a learning disability.

In this update you can read about some of the work that is happening and some of the ways that people with a learning disability have been involved.

I hope you enjoy reading this newsletter.

Simon Stevens

Forum event update



On 21 July 2016, 75 people came to the NHS England Forum for People with a Learning Disability and/or Autism, and their Families, Carers and Supporters.

1 What did the Forum talk about?



People who went to the Forum were asked to help write guidance for people who plan and pay for services.

This is to make sure those services help people.



Guidance is something that helps people know what to do.



The 4 areas they talked about were:

1. Community support for children, young people and adults who have behaviour that is challenging.

2. Supporting people who have been or might get into trouble with the law.

This is sometimes called **community forensics**.

3. Non-secure settings.

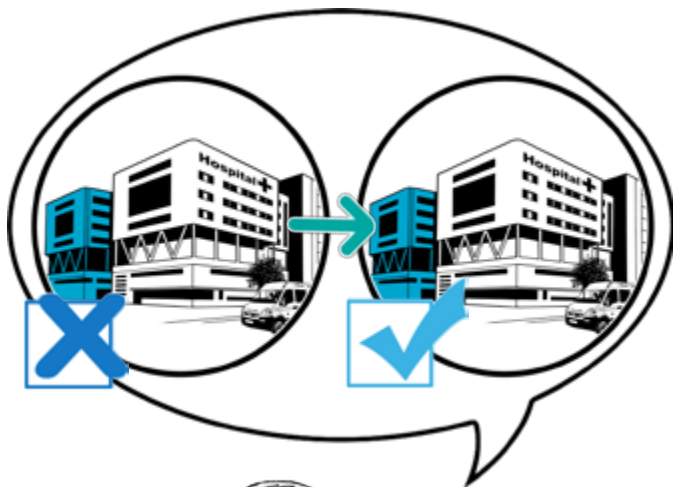
This is about what good care and treatment should look like in hospital.



4. How mainstream services can work better together and share skills. This can improve the physical and mental health of people with a learning disability and/or autism.

This is sometimes called the **learning disability liaison function**.

2 What did people say?



People who went to the Forum told us what professionals could do to make services better for people with a learning disability and/or autism, and their families.

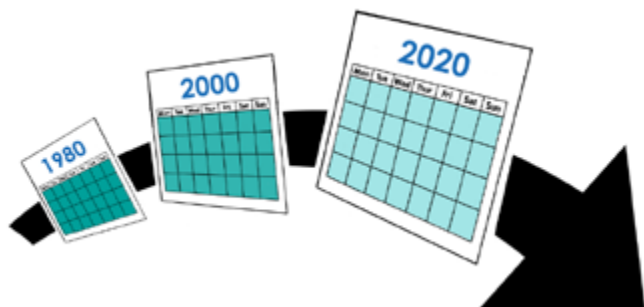


They said professionals should:

- Work together and understand what each other is doing.
- Do what is right for the person instead of what is right for the service.
- Have more people working in services and hospitals that are learning disability trained. That way people can always get help when they need it.



- Make it easy for people to get help quickly, so that things do not reach a crisis point.



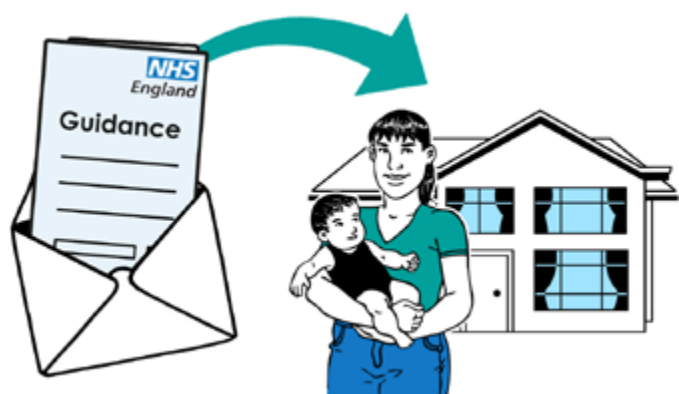
- We should plan for people's whole lives.



Planning should involve families and people who provide support.



- Learn from people's experiences and employ people with a learning disability and/or autism.



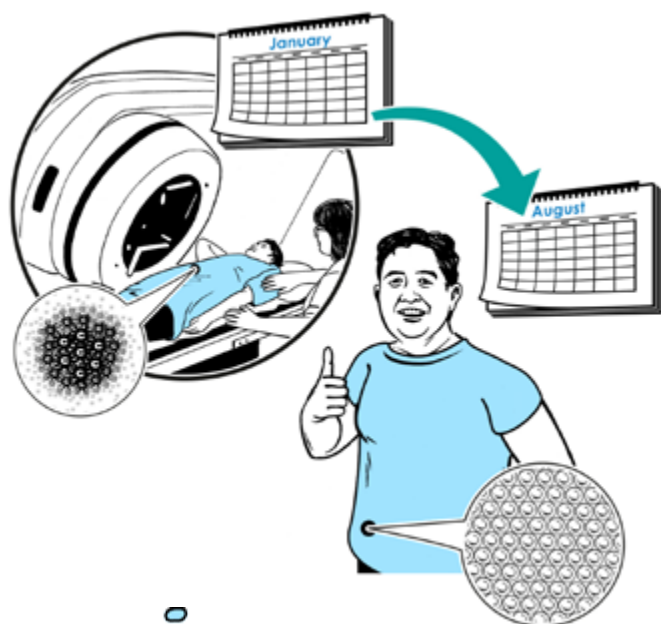
We would like to thank everybody who came to the event and helped write the guidance. We will send you a copy when it is ready.

Cancer screening

Improving access for people with a learning disability



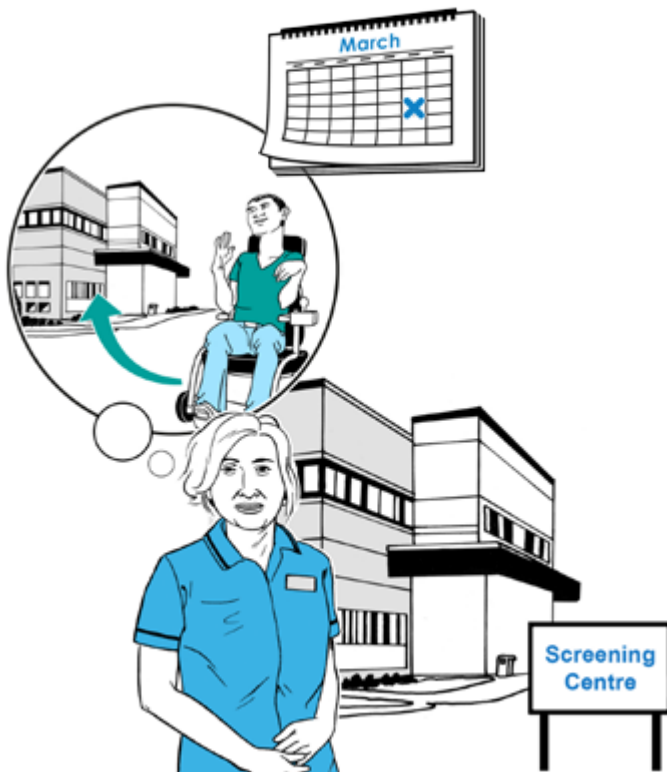
Everyone should be asked if they want a cancer screening test.



Finding cancer early will give you the best chance of treating it so you can get well and live a healthy life.



The North East and Cumbria learning disability network ran an event about cancer in June 2016.



At the event, people said it is important to:

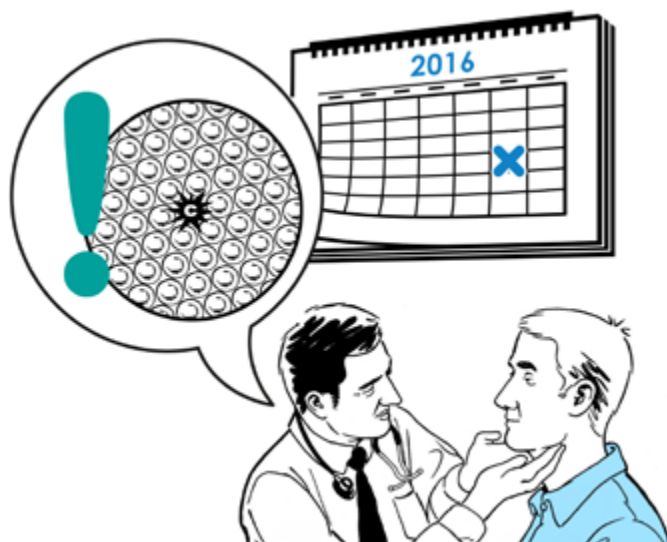
- Make sure cancer screening centres know that someone has a learning disability when they go for tests.



This is important because the nurse or doctor needs to communicate in a way you understand.



- Make sure information about cancer screening is in easy read.



- This is important because a person with a learning disability will find information about cancer a lot easier to understand.
- Encourage more people with a learning disability to have an annual health check. An annual health check is a check that happens once a year.
- This is important because sometimes at an annual health check medical staff might find a serious illness like cancer.

This means it can be treated sooner.



- Have staff at cancer screening centres trained in learning disability awareness training.

Nurses can better communicate and support patients with a learning disability if they have had training.

- Train staff at cancer screening centres about the Mental Capacity Act.

This is important because the law says that people have a right to make choices about their own health.



- The Mental Capacity Act says that people must get the right support to make the best choices.



After you have read this article you can ask your doctor for an annual health check if you haven't had one already.



You could also ask if your doctor has any easy read material about the signs and symptoms of cancer.

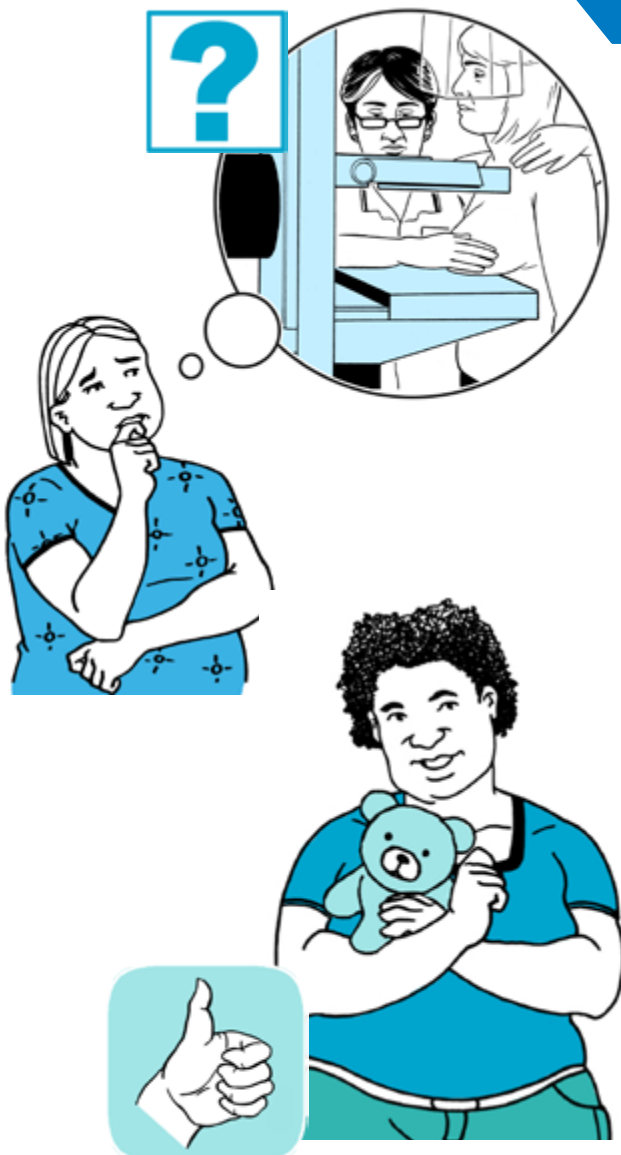


Breast cancer screening research



Middlesbrough Council worked with a group of women with a learning disability to find out what they thought of breast cancer screening.

1 What did the women say?



- Most women didn't know how breast cancer screening is done or why it is done.
- Some women said they would feel more comfortable if they were given something like a teddy for comfort.



- Some women said that taking someone they knew to their breast cancer screening would make them feel more comfortable.

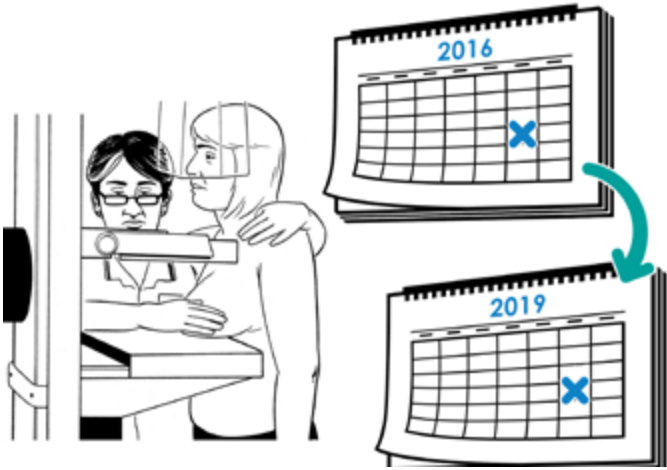


- Some women are scared by the machine as they don't know what it will do.

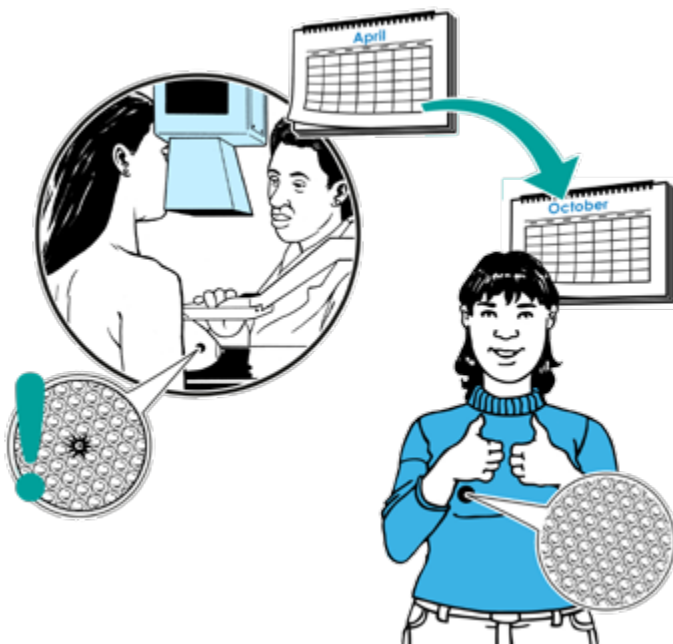
2 What did the women find out?



- Women who are over the age of 47 will get a letter inviting them to a breast cancer screening test.

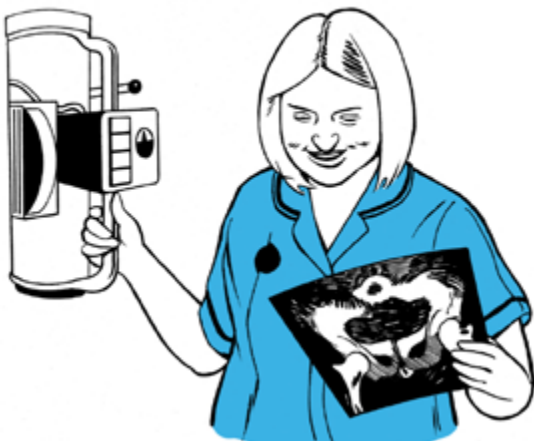


- Breast cancer screening tests are done every 3 years.



- Breast cancer screening can save lives by spotting early signs of breast cancer.

3 What did the radiographers find out?



A radiographer looks at scans of people's bodies to find out if they have an injury or an illness. They also care for people with cancer.



From working with this group the radiographers found out:

- How to speak to people with a learning disability.
- What women with a learning disability might be scared of.
- What things they can change to make people feel less worried and scared about breast cancer screening.



The group has made a video to help more women with a learning disability understand about breast screening services.

You can watch it here:

[www.youtube.com/
watch?v=fZNDHTSQfUk](https://www.youtube.com/watch?v=fZNDHTSQfUk)

This will help some women.

More still needs to happen to make sure people with a learning disability get the same access to health services as everyone else.

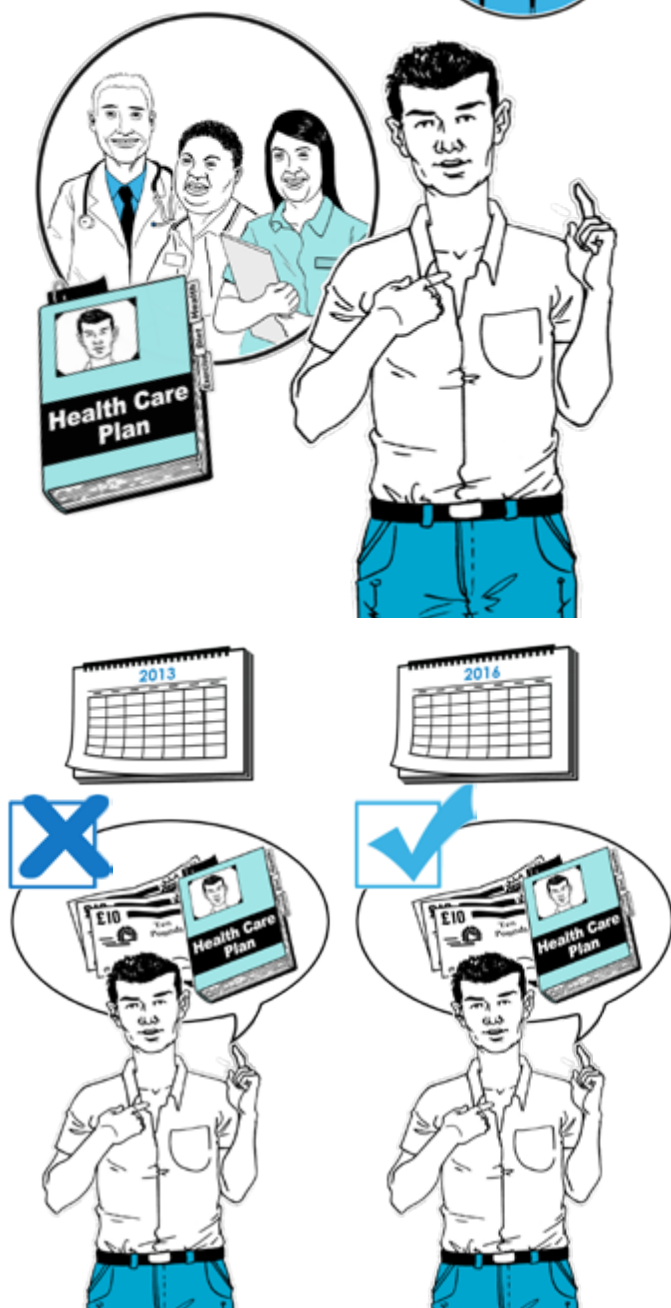
Personal health budgets

1 What is a personal health budget?

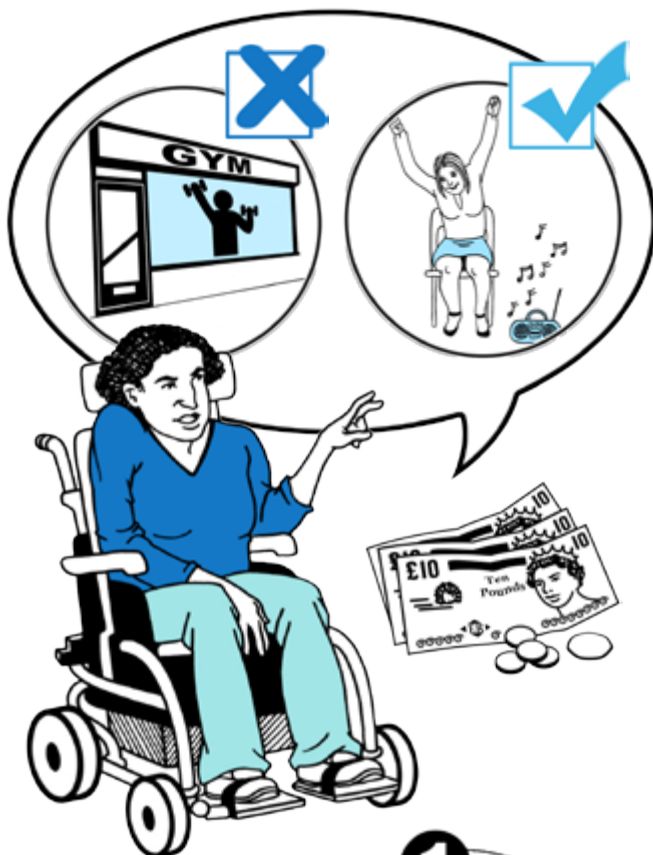


A personal health budget is money given to you to pay for your care and support.

If you have a personal health budget it will be part of your care plan. You can agree the best way to spend the money with your doctor, nurse or care manager.



The money has always been there for your care but now you can choose how you spend it.



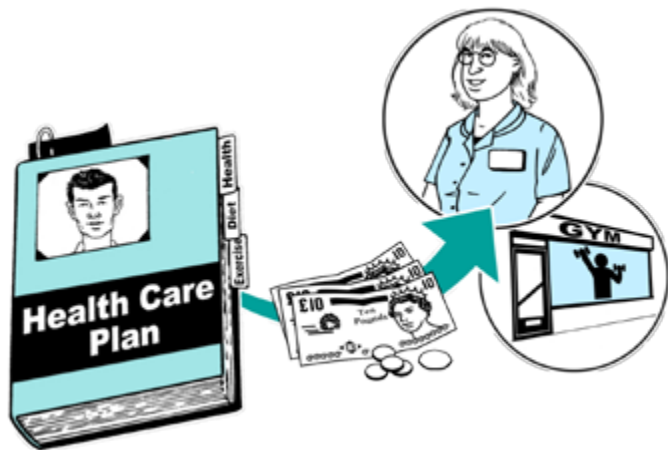
A personal health budget gives you more choice and control of your life:

- You have a say in your own healthcare.

- You choose how the money is spent so it meets your needs.

- You have the choice to live with your family or in your own home.

2 What can I spend the money on?



You must spend the money you are given on things that keep you healthy and safe.

These things must be written in your care plan.

These things could be:

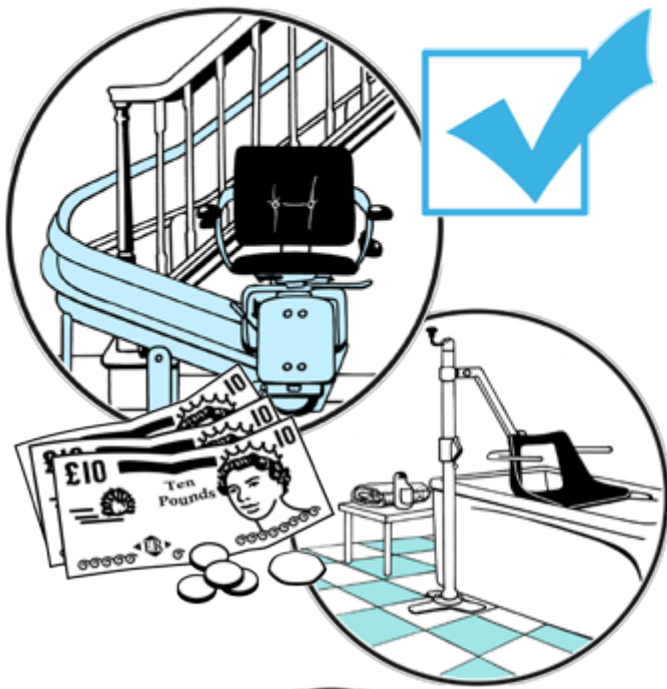
- A personal assistant to help you do everyday things like shopping and cooking.



- Activities that make you feel good and are good for your health.



This could be dancing, sports classes and going to the theatre.



- Things that make your life easier like special equipment, and changes to your home.



You cannot spend the money on things that are bad for you like alcohol, cigarettes, or gambling.



The NHS will still give you some things for free.

An example of this is going to hospital if you have an accident.



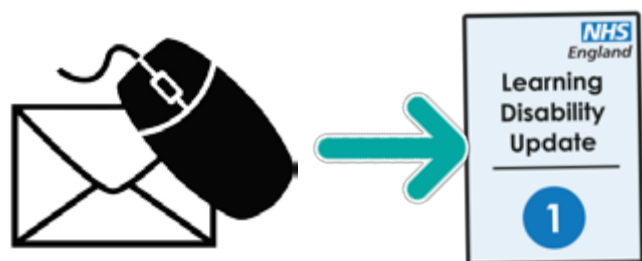
You can talk to your doctor or your care planning team to see if you can apply for a personal health budget.



If you want more information about personal health budgets you can look at this website:

www.england.nhs.uk/healthbudgets/understanding/learning

Transforming care partnerships



Local
Government
Association

NHS
England



Transforming care partnerships are working to make services in a local area work better.

If you want to know more about transforming care partnerships you can read about them in the first learning disability update newsletter.

You can ask for a paper copy of the newsletter by emailing:

LDEngage@nhs.net

The Local Government Association and NHS England want to help transforming care partnerships work with people and families. To do this they will:

- **Work with people and their families.**



- Put people at the centre of their own care and support.
- Make sure people feel confident to use their voice.

We hope to employ experts by experience to lead on work in the Midlands and East, North, South, and London regions. To do this we would:

- Use a co-working model. Co-working means that an expert by experience works with someone who understands that people with a learning disability and/or autism should be included.



- Help transforming care partnerships work together with people and families to help plan and deliver local services.



- Work together. The experts by experience in each region would meet regularly.

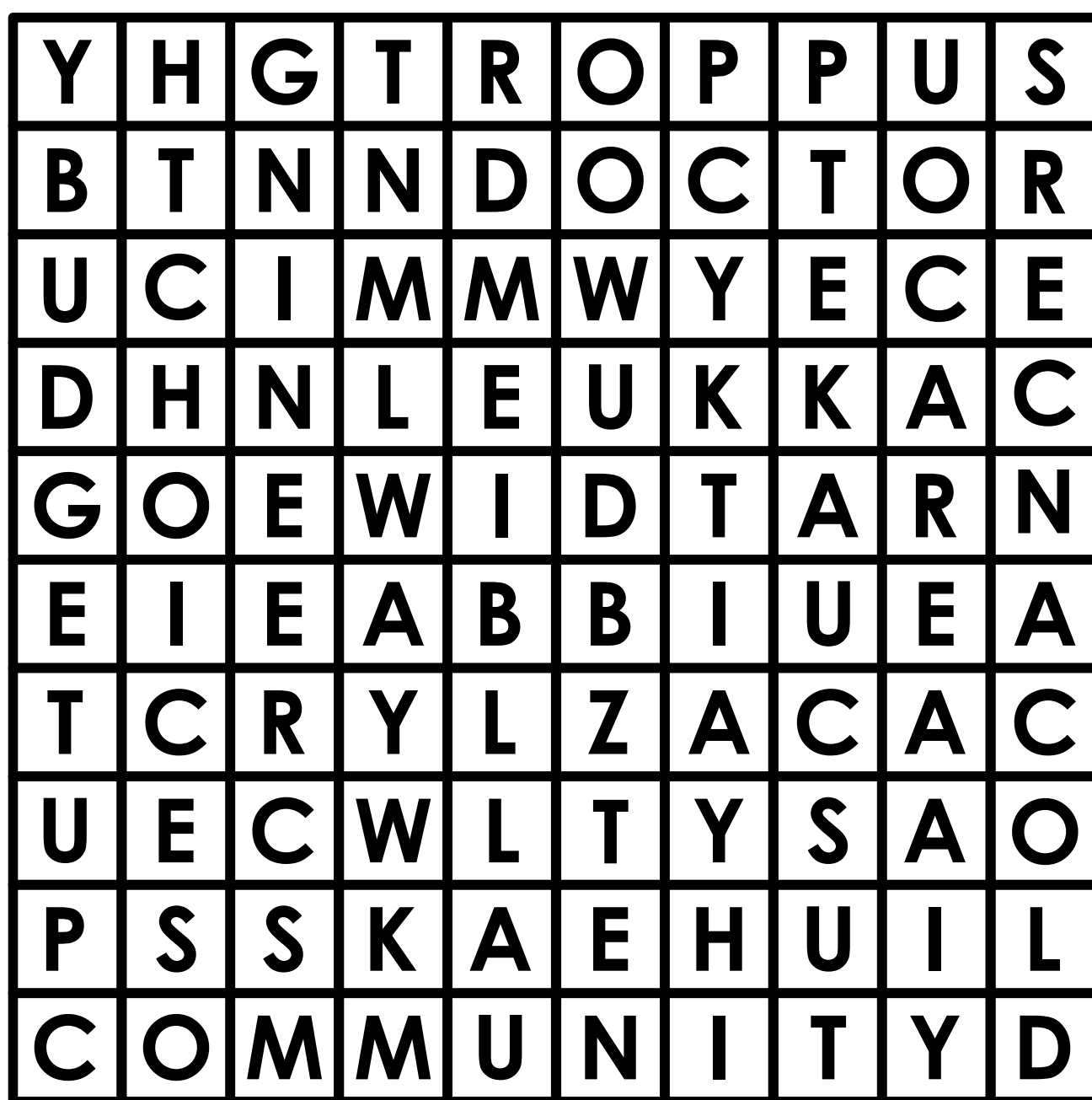


This is still just a plan. You will get more information when we know more about the jobs.

Word search

Try and find these words in the word search below:

autumn, budget, cancer, care, choices, community, disability, doctor, health, medical, screening, support.



Notes

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

Contact us



**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



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info@changepeople.org

