



Department
of Health

Making Rights Better and Listening to People



**For people with Learning Disabilities, Autism
or Mental Health Issues**

**We are asking questions about how to make people's lives
better. Tell Us What You Think!**

May 2015						
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Information Booklet

Please tell us what you think by 29 May 2015.



**This is an EasyRead version of:
No voice unheard, no right ignored –
a consultation for people with learning disabilities,
autism and mental health conditions.**

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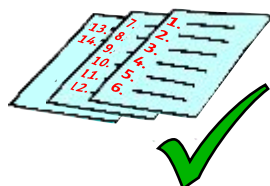
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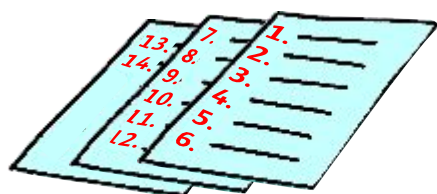


About this booklet.

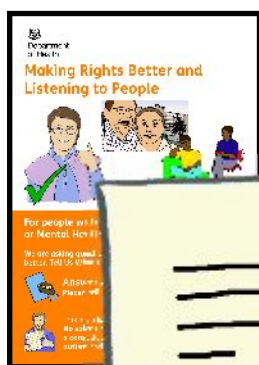
We are asking questions about how to make people's lives better.



In this booklet we give you some information about things we think might need to change



The information is numbered from 1 to 14, so you can see what information goes with each question in the Answers Booklet.



Then we would like you to answer some questions in the separate Answers Booklet that you can fill in and send back to us.

The details about where to send it are in that booklet.



We hope you feel able to take part. Thank you for your help.



Living away from home in the past.

We know from the past that some institutions and long stay hospitals were bad places to live in.



Too many things went wrong. People were not treated well. They were away from their **communities**.



Since then, things have changed. Most of the institutions and long stay hospitals have been closed over the past 40 years.



But, there are still hospitals and care homes that people are sent away when it is not right for them and it is not their choice.



Sometimes people are held in hospitals and are not allowed to leave. This is under law called the **Mental Health Act**.



We still sometimes hear in the news about bad things that have happened in some places.



People who have to live away from home may have a learning disability or autism or they may have mental health issues.



We know having to live away is often not good for people.



People have said they do not feel listened to.



They have not been helped in their local area.



We want to know what you think about ways to stop people having to live miles away from their families and loved ones.



We want to ask you some questions about people's rights.



We want to know your ideas about changing this for the better.



Then it will be up to the next **Government** to decide what to do.



1. My right to be independent and part of the community. Living in a home I have chosen.



Helping people stay close to their communities

Disabled people have the same rights as anyone else. Like anyone else, disabled people want to:



- be part of a family



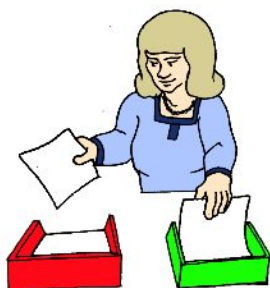
- be members of a community



- have good friendships



- have a social life



- have opportunities to work.



All of this is important for what is called **'wellbeing'**.

Wellbeing is about having good physical and mental health.



Wellbeing covers all the things that support being part of the community.



This could be things like:

- taking part in things the way other people do



- having opportunities to get paid or unpaid work



- taking part in education or training



- having a social life.



The new **Care Act** law says that **Local Authorities** who deal with social care must always think about your wellbeing.



The law also says people have to be listened to.



It says people should be asked their choice about where they live. It needs to be the right sort of place to meet their needs.



Guidance on the Mental Health Act also says people should be as close to their choice of home or their family as they can be.



We think the **National Health Service (NHS)** could have the same rules as the Local Authority about a person's wellbeing.



This could cover people with learning disabilities and autism and mental ill health who are most likely to have to go to hospital.



We think those who buy services for the Local Authority and the NHS could help people by having to think about how they:

- stay close to the community that is important to them
- keep good links up with family and friends





- can still take part in work, education, training and a social life



- live somewhere as open as possible.



Having enough services in the community

There have to be enough good services in the local community to support people well. Then people can stay there even if they have problems.



People who plan and buy services are called **commissioners**.



They should only buy services that are good and help wellbeing. Some services that do not provide the right sort of care will need to be closed.



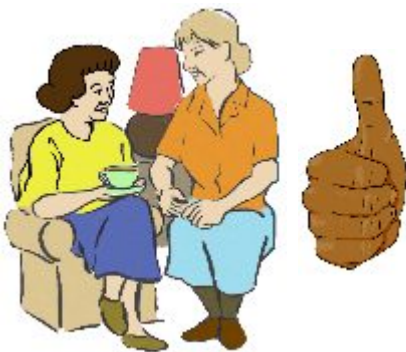
The Care Act says that Local Authorities have to try to make sure there is a good mix of services in their local area.



They have to try to make sure there is a choice of different types of services for people.



At the moment this new law does not apply to the NHS.



We think the Local Authority and NHS need to buy enough of the right sort of services.



These should be in local areas and help people to stay at home.



We do not want people with learning disabilities, autism or mental ill health to have to go away. If they do not have to or choose to.



But they can be the people most at risk of being sent away.



Assessment and treatment in the community and the Mental Health Act

Often, when people with learning disability or autism are sent away from home, it is for assessment or treatment under the Mental Health Act.



An assessment is where doctors or other professionals see if a person can be kept in hospital where they are not free to leave. They have to follow the law in the Mental Health Act.



The assessment will also show where people need health treatment or support.

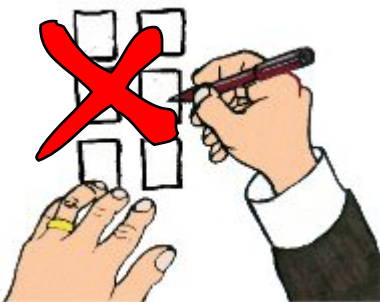


Under the Mental Health Act there are forms that have to be filled in.

They ask why the person has to stay in hospital.



We think the forms should ask why they cannot be assessed or treated in the community.



We want to change the questions on the forms.



We think this will help cut down the number of people who are held in hospitals under the Mental Health Act.



2. My right to be listened to and have my wishes acted upon.

My right to challenge decisions about me.



Knowing your own rights and being involved.

People have a right to take part in planning their own care and support. A lot of our policy and law says this.



But many people say they feel they have no power. They feel their rights are not clear.



We think the person should be given clear easy read information about what is happening and their rights.



This could be done with family or advocacy support.



This could be the job of a named professional (like a social worker).



This would have to say why the NHS and Local Authority think:

- the person should go to hospital



- the person should stay being treated in hospital



- the person should have to live away from home.



They would also have to say:

- why there is no closer or community place for the person to go to



- why that could not be sorted out in a short space of time



- when this will be looked at again.



The right to say you think the wrong choice has been made and to ask for change



The NHS or Local Authority should have to ask people what they think.



It should not be up to the person to have to ask to have a say. This should happen anyway.



It would help if the NHS or other professionals had to ask for people to agree.



For example, they can be asked if they agree that they need to go to another place to live.



If people have agreed to go somewhere for help they should also be able to change their mind.



If they want to move nearer to home later on they should be able to ask to do so.



They should also be able to ask to leave the service and go home.



It might work well to put this into law or into guidance for the NHS and Local Authority.



It will say clearly what they have to do.

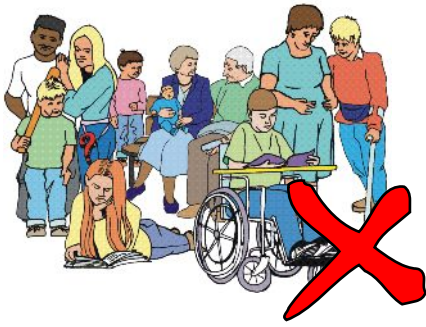


Planning care and leaving to go home

People should be able to have a say in their care plan at the point they go into hospital.



There should also be a plan about when they will leave the hospital. It is already set out that this should happen.



But, we know it does not work for a lot of people.



We think **all** people who go into hospital should have a plan about when to leave.



This will help plan the services that should be ready for them when they go home.



People (and their families and advocates if wanted) should all have a say in this.



Information should be easy to understand.



Challenge to being held under the Mental Health Act

Many people with a learning disability or autism are held in hospital by law under the Mental Health Act and are not free to leave.

There are many checks that already have to take place.



At the start, the person has to be asked about how they feel and have their views listened to.

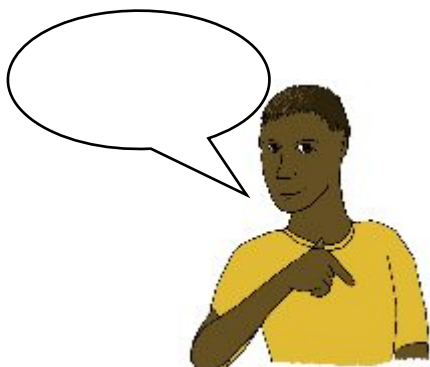


We think people should be able to challenge if they don't think they have been listened to properly.



When they are being held in hospital, people should be involved if decisions are being made about them staying there.

3. Involving people and their advocates.



Self-advocacy needs to be an important part of what happens everywhere. Self-advocacy means people speaking for themselves.



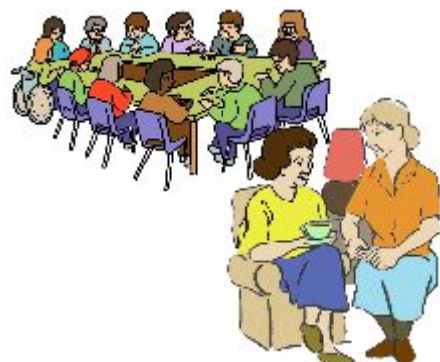
We think that people working together is very important.



People and their advocates need to be taken notice of.



We think that there should be people with learning disabilities or autism and families on the Boards of services.



They should have a place in helping to run and control services.

This way services will be set up the way people want them.



4. Helping people use their rights.

Support from Independent Mental Health Advocates, families and social workers.



Some people need more help to put over their views, feelings and beliefs.



They may need support to be able to do this.



This support can come from:

- Family – including “**nearest relatives**” under the Mental Health Act



- Advocates – including **Independent Mental Health Advocates**



- Professionals - including social workers.



The Care Act has new rights on advocacy.



Independent Mental Health Advocates

Under the Mental Health Act, some people have the right to have an Independent Mental Health Advocate if they choose and are getting treatment.



An Independent Mental Health Advocate is a special kind of advocate who helps you if you have mental health problems and are getting treatment under the Mental Health Act.



We would like more people to make use of an Independent Mental Health Advocate.



We would like anyone who does not have the **mental capacity** to make their own decision about having an Independent Mental Health Advocate, to have one.



Having **mental capacity** means being able to make your own decision about something.



This could be by asking hospital managers to do things to make this happen.

Nearest relative



A person's **nearest relative** is a person who has important rights and responsibilities under the Mental Health Act.



At the moment, who the “nearest relative” is is set down by law.



Sometimes, close family members or people’s main carers are not their “nearest relative” in law.

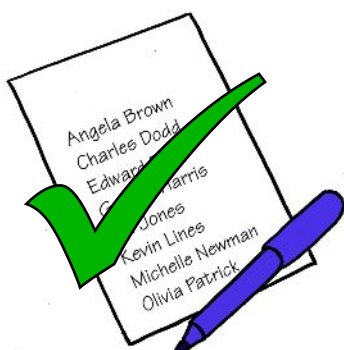


This does not seem right.



We think people should be able to choose who they want to be their own ‘nearest relative’.

This will need a change in law.



The list we have at the moment could be used if it was still needed.



Social workers

Social workers work with and support people.



But sometimes they do not take part as much as they could do.



They could take part in plans, decisions about going to hospital and reviews.



People and their families and advocates should be kept up to date about what happens.



Social workers could be the people to pass this information.

The social worker would make sure they had all the information and were being taken notice of.



People should know the name of their social worker who has to:

- make sure the person's plan is as near to home and their community as it can be



- make sure that community based services have been thought about first



- make sure people are working together to agree their care and support



- make sure everyone has all the information they need and are kept up to date.

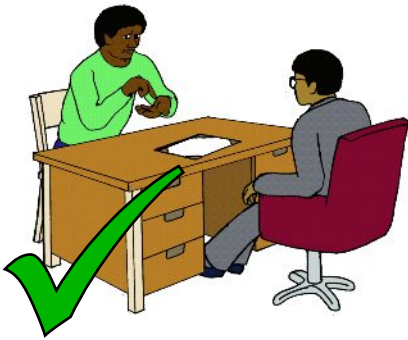


People would have a right to choose someone else to carry out this role if they want to.



5. Support if something goes wrong.

We often hear that it can be hard to know what to do or to get support if something goes wrong.



It should be easy for people to complain.



Lots of changes have happened lately.



We need to find out if anything else is needed to make this easy.

6. My rights and the Mental Health Act.



How the Mental Health Act is used for people with a learning disability or autism.



The Mental Health Act is a law about treating people with serious mental health problems in England and Wales.



It can be used for people with a learning disability in some serious situations when the law says.



For example, this could be where someone has very challenging behaviour and might hurt themselves or someone else.



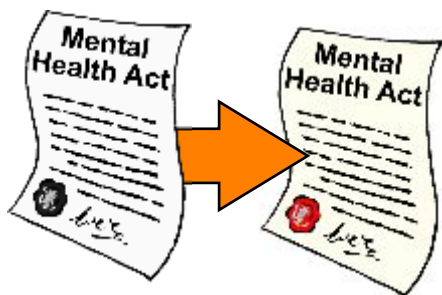
Some people think people with learning disabilities or autism are treated or held in hospital because of their label.



This could make people's physical and mental wellbeing worse not better.



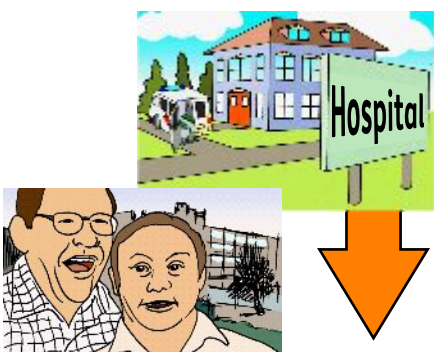
We think that the Mental Health Act needs to be very clear about who and what it is for.



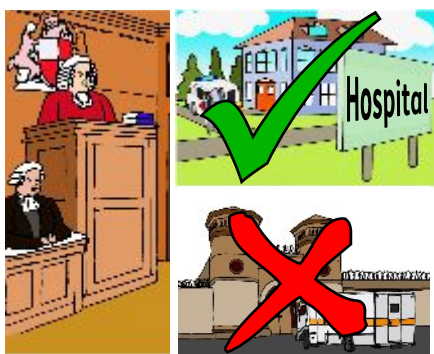
There are some things we could change in the law.



For example, say people with learning disability or autism can't be sent to hospital against their wishes under the Mental Health Act or only sometimes.



This could be by describing a smaller number of situations or reasons when a person with learning disability or autism could be held in hospital.



Or this could only happen if the courts say they should go to hospital so they don't go to prison.



7. A single path for Mental Health Act assessment and treatment.

The Mental Health Act can be hard to understand.



People can go for assessment or for treatment in hospital under different rules.



We want to look into changing the law.



We are thinking about **one** clear path for holding people in hospital for assessment and treatment.

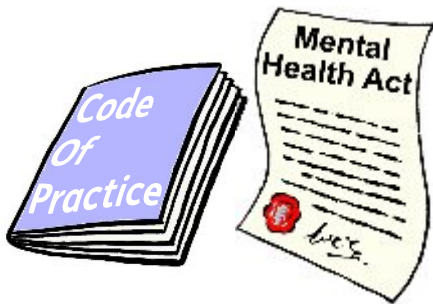


This would make it easier for people to understand their rights.



8. The Mental Health Act and people who plan and buy services for the NHS.

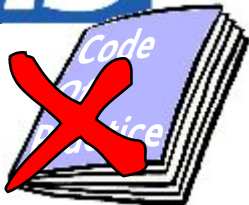
People who plan and buy services for the NHS should have to make sure that the Mental Health Act works well.



At the moment there is a 'Code of Practice' for the Mental Health Act which gives guidance all about good care.



Hospitals have to follow this guidance unless there are really good reasons for not doing this.



But, the law does not say that the people in the NHS who plan and buy services in hospitals have to follow the Code of Practice.

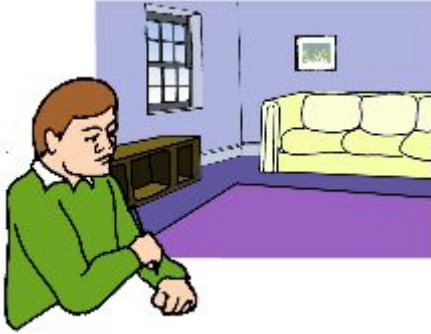


We think the law should say that the people in the NHS who plan and buy services should also have to think about and follow what the Code of Practice says, like hospitals do.



9. Using police cells and holding people in hospital instead of prison.

Use of police cells



Sometimes, when people have a mental health crisis, they are taken to a **place of safety**.



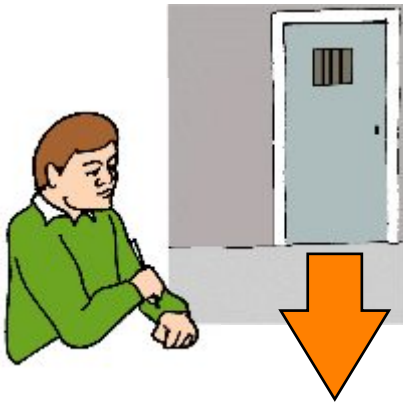
A place of safety is a safe place for people so they can get help if they need it.



It is usually a hospital but sometimes cells in police stations are used.



The government looked at the law about places of safety.



It wants to:

- cut down on police cells being used a 'place of safety'



- make sure no children and young people are kept in police cells



- where people are kept in police cells, to make sure it is only for a short amount of time



- see if people from other services could take people to a place of safety and not just the police.



Patients who are held in hospital under the Criminal Justice System

Some people are patients under the Mental Health Act through the Criminal Justice System.



Instead of going to prison they have been put into a hospital.



They are called '**restricted patients**'.



They may be able to live in the community under strict rules.



This will be to keep themselves and other people safe.



But, some 'restricted' patients cannot leave a hospital to live in the community in a safe way at the moment.



This is because at the moment they are not allowed to live in the community if they are held in a way that they are not free to leave. This is called a **deprivation of liberty**.



So some people are in secure hospitals when they might be able to be in the community under strict rules.



We are thinking about whether the law should change to allow this to happen.

10. My right to control my own support and services with a personal budget.



Personal budgets

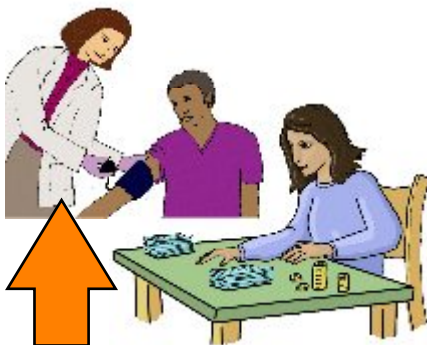
Services should start from the person's needs. People know their own needs and wishes.



A personal budget is the money used to buy your care. It helps you know how much different services cost and helps you choose how the money is spent.



People can already have personal budgets for their social care support. They are also being used more now for health services.



We think personal health budgets can help make sure people have more control over their own lives and choices.





We think a personal health budget would work well for people with learning disability or autism.



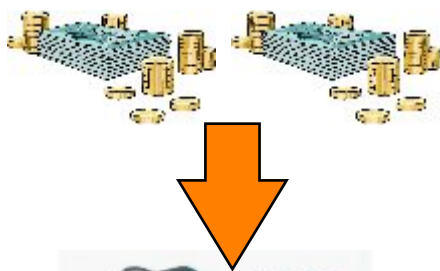
It could pay for care and treatment in the community.



This could be for some people who are in mental health hospitals at the moment.



Or for people who have special support called the Care Programme Approach.



11. Putting different sets of money together (pooled budgets).



People who buy services for the NHS and Local Authorities sometimes put their money together for mental health and learning disability services.



But this does not happen everywhere.

When it does not happen, it can stop a person getting the care and treatment that is right for them.

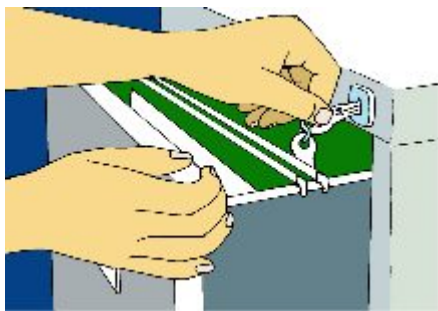


We want to make sure money is put together to give better local services.

We want to look at setting this up throughout the country.



This could mean there was money for people to move back into their communities when they are ready.



12. Sharing Information.

Personal information should be kept private.



But important information about what care people need sometimes has to be shared.

This is to make sure people get the right care.



Commissioners are the people who plan and buy the care.



They need to know the right information about what care people need and are getting.



At the moment this does not always happen.



If possible, people should be asked if they want information about them to be shared.

Sometimes this can be hard to do.



The people providing care may not want to share or ask people if they want to share. This may be because there are problems they do not want other people to know about.



We think that it should be the law that people who are providing care at the hospitals or care homes should have to share information with commissioners.

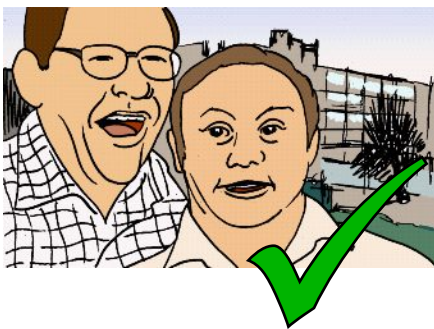


Sharing information will help get the right care for people or help if there are worries.



13. Who is in charge of supporting my physical as well as my mental health.

People should know who looks after a person's physical health if they have a mental health issue.



This is very important for people with learning disabilities or autism.



A person's physical health needs must also be looked after when they are in a mental health hospital.



We want to make it very clear who has to do what, including:

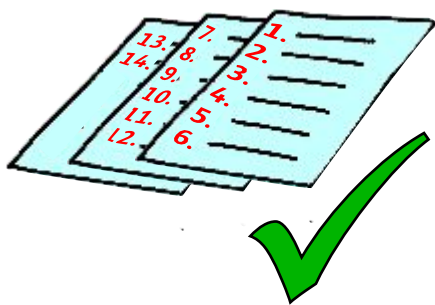
- who buys physical healthcare in the area where people are staying in a mental health hospital



- what the hospital has to do

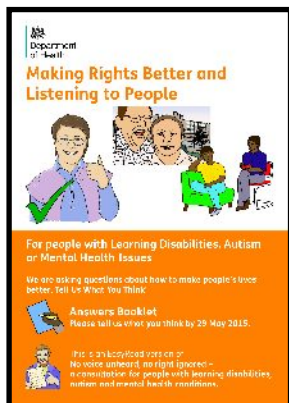


- what the main doctors have to do.



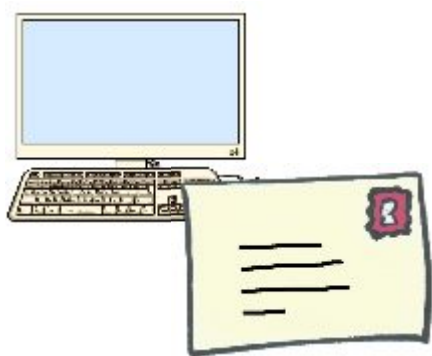
14. Last question.

Please tell us anything else you think is important about these changes.



What to do now

Please look at the questions in the Answers Booklet.



You can fill in the answer booklet on a computer or you can post it back to us.



The address and contact details are at the end of the Answers Booklet.



Thank you for your help!



This paper meets the European EasyRead Standard.



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