Developing social care: Service users' vision for adult support
What is in this report

About this report page 2
What service users said about social care page 9
How social care is now page 13
How to make things better in social care page 23
How service users would like social care to be page 27
What people with learning difficulties have to say page 44
Word list page 60
What is this report?

The report was written in November 2004. It is a report of what groups of service users said when they were asked what they thought about social care. In this report, asking a group of people questions is also called a consultation.

This report is part of the Department of Health’s program called New Vision for Adult Social Care.

This report says:

- what service users think about social care.
- how service users want social care and services to be in the future.
- what service users think are good things in social care.
- what service users think could be better.

How to read this report

This is a plain English short report of the full report called A new vision for adult social care: Start from our experience. Service users vision for adult social care.

You can get the full report from the Social Care Institute for Excellence (SCIE).

The words written in quotes ‘like this’ are things that were said by service users. The words have not been changed. If there are extra words to explain what a service user said, it is written in brackets [like this].

There is a word list at the back of this report to show what some of the words mean. Words in the word list are written in blue.

You don’t have to read all the report. You can read just the parts that you want to know about. Each part of this report has one or two sentences at the start to tell you what that part is about.
Who wrote this report?

An organisation called Shaping our Lives asked service users what they thought about social care. Shaping our Lives is a user-controlled organisation made up of service users who want to have more say.

Shaping our Lives is not part of the government.

Shaping our Lives has a lot of experience working with service users and asking questions in groups.

Peter Beresford, Michael Shamash, Vic Forrest, Michael Turner and Fran Branfield wrote this report about what service users said.

Who took part?

112 different service users from all over England answered questions and said what they thought about social care.

More service users wanted to take part, but there was not enough time and people to talk to everyone.

65 women and 47 men took part.

People were not asked their age, but this was guessed. There were people from about 19 to 80 years old.

One in four of the service users that took part were from black or minority ethnic groups. There were 31 black and minority ethnic service users and 81 white service users.

Asian, African and African Caribbean service users, and service users with parents from different countries took part.

There were service users who were from (or who had family from) China, Iran and other Middle East countries.

People were not asked if they were gay. But in three groups, people said things that might mean they were gay.

Shaping Our Lives wanted to make sure that a lot of people with different learning difficulties could join in, so there were three groups just for people with learning difficulties in London and Bournemouth.
Seven people with learning difficulties joined in the groups and 15 took part in the groups only for people with learning difficulties.

The consultation made sure that people who don't always have a chance to have their say could join in.

People were not asked to join the groups just because they are the biggest group of service users.

There were people in the groups who were:
- older people
- deaf and used British Sign Language
- someone with a problem with their face
- care leavers
- mental health service users and survivors
- people with learning difficulties
- parents
- parents with learning difficulties
- people with experience as refugees
- people with more than one disability
- deaf and blind
- people with physical disabilities and learning difficulties
- people with physical disabilities who also used mental health services.

The service users who took part have used many types of social care, including:
- equipment from the community
- day services
- help in the home
- services from service user groups
- residential services
- services to help people use direct payments
- social workers
- key workers
- floating support workers
- other social care workers like health, housing and other workers.

The service users who took part were:
- service users who paid for their care and services with their own money
- service users who used local authority services
- service users who got direct payments.

About the questions

The questions were thought of by service users. There were 13 different question sessions in September 2004.

The questions were asked in:
- London
- Essex
- Southampton
- Wiltshire
- Manchester
- the North East
- Shropshire
- Worcester
- Liverpool
- Bournemouth.

People who lived in cities and in the country took part.

How were the questions asked?

Shaping our Lives did a lot of planning before the questions were asked, to find out what would work best.

There was a facilitator for each group who made sure everyone could have a say and talked about the right things. Service users talked about and around the questions.
Shaping our Lives asked groups in each area to ask the questions to their own service users.

Each group had the same questions.

Everyone said it was ok for the answers to be put on tape. Each group took notes and told Shaping our Lives what kind of people were in each group.

A report was written in October to say how the first groups were doing. A report of everything was written in November 2004. The plain English report was written in May 2005.

Who asked the questions?

The questions were asked by people who had used services.

One local organisation asked a disabled consultant to ask the questions.

Other organisations used people already working for them.

In one group, an experienced disabled woman from the area was the facilitator.

An experienced black service user researcher asked the questions with a group of black mental health service users.

Two experienced service user researchers working with Shaping Our Lives asked the other groups.

The person who was the facilitator for the groups of people with learning difficulties had done a lot of work with people with learning difficulties.

How did service users feel about being asked?

Service users wanted to take part and have their say. There was a lot of talking.

Everyone wanted to say something about how they thought things should be, what was needed for the future and what was wrong with things now.

Service users were not tired of saying what they thought because they knew this was important.
They felt that their ideas had been asked for by Minister Stephen Ladyman, and this time their ideas would be heard.

People who took part wanted to know what was going to happen next.

How big were the groups?

The smallest group had two people and the largest group had 17 people. Most groups had about eight or 12 people.

The groups of people with learning difficulties had only five people so that they could all have a say.

How long did people talk for?

People talked in groups for about two hours to five and a half hours. Most talked for about three hours.

People had breaks whenever they wanted or needed.

Why is this report important?

This report is a lot of important information for the future.

This is the best research we know of that has been done like this.

The first time the government wrote a plan for how adult social care should be, it did not ask service users what they thought. The government has now spent the time to ask service users what they think.

In the past, social care has changed because of what service users wanted.

Service users know how to make change happen and know what works.
What happens now?

The government has an idea called for A New Vision for Adult Social Care.

This idea started because new things were happening for children's social care.

The new plan for adult social care and this report are going to help plan how social care will be in the future.

The government is going to write a Green Paper. This will say how adult services should be and how to make changes happen.

Thank you

All service users who took part were paid for their time and their experience. People also got paid for travel and other costs.

There are a lot of people who helped make this report. Thank you for your help. The people who helped are listed in the full report.
What service users said about social care

This part is about what service users said about social care. It is the main things that people said are good and bad about social care. It is also about how social care can be better and what things people would like in the future.

All people's lives need to be understood and appreciated.

'Good support is a sign of a good society. We just want to have a normal life and be able to do the things that everybody else does and takes for granted.'

Things that must be done:

- There must be enough money for social care services.
- There must be enough people working in social care services.
- Service users should be charged less money for the services they use.

Problems that need to be fixed:

- Not being able to get help each time.
- The uncomfortable feeling when services change or are different from what service users had been told.
- Feeling like services could be stopped at any time.
- Services not being good enough.
- The same services not being there for all to use.
- Not having good enough ways of getting services and help.
- Not always being possible to get good social care.
Problems with people working in social care:

- It is very hard to get good help or good enough help from workers and agencies.
- There is not enough help and people working in social care.
- Sometimes service users are bullied by people working in social care.

Problems with the way social care works:

- All departments work differently and they do not work together.
- People working in social care follow rules and have too much paperwork. There is not enough talking and common sense.
- Services will not change even a little.
- The way of working is not always a very good way.
- Things are not the same for all service users and service users are not always treated fairly.

The things that service users are afraid of need to be looked at and talked about if something is to be done to make social care better.

Things that could make social care better

**Services:**

- A choice of good day services and good services that help people get a job, not only one of these choices.
- Having services that are good for service users from black and minority ethnic groups.

**People working in social care:**

- Having more workers from black and minority ethnic groups.
- Getting people who work well with service users to train some of the other people working in social care.
● People working in social care getting good, useful training that could make a difference in how things are in social care.

**Ways of working:**

● Making more examples of things that work well.
● Paying more attention to doing the things that service users say they like.
● Make services simple and easier to use and understand.
● Talking about social care using words that show that people are being helped, not cared for.
● Having ways for service users to say what they think about services, or say when something is wrong, without worrying that they might get in trouble for saying it.

**What service users think is important for better adult social care**

**About service user involvement:**

● Services being good enough because service users themselves have said they are good enough.
● Having choices that service users have said they want.
● Having good ways for service users to join in with services.
● Having more services that are thought of and run by service users.
● Listening to what service users have to say.
● Service users saying what makes good services.
● Social care changing because of service users saying how things in social care should be.
● Social care that makes what the service user want the most important thing.
● Social care that helps make service users stronger so they can join in and have real choices with the community.
About services:

- Direct payments that are easier to use and get used.
- Making it easier to get help and information on services.

Ways of working:

- Knowing how to work and have ideas for social care, not just personal care.
- Social care being seen as a good and important thing.
- Different teams and departments working together to make social care better.
- Making it important that all service users get treated the same.
- Making it important to see the good things in everyone's differences.
- Social care that does not see the service user as a problem.
- Social care that looks at the way people see service users and the way that the community treats service users.
- Social care that helps service users to do things for themselves by giving them the help they need to live as they want to.
- Social care that looks at service users' rights.
How social care is now

This part is about how service users find social care now. It's about the good and bad things about the services they get.

Service users talked about good things in social care. They also talked about how the bad things in social care made them feel.

People could think of more bad things in social care than they could think about good things in social care.

Some groups really feel that social care has got worse in the last few years. They said there was less help than before and the help is not very good.

Problems with getting a service

Getting a service was sometime very hard for service users. There seemed to be no one way to get a service.

If the worker doing an assessment was helpful, then a service user might get a good service, otherwise they would not.

Some workers were good at getting service users to speak up for what they wanted but some did not.

The bad assessments only give what services can do not what is needed, and don't make the service user feel in charge.

Service users said that the assessment tried to get them quick help but not the best help.

Service users who could not hear, see or talk, or service users with more than one need, had the hardest time getting a service.

‘Care plans need to be done properly and people need to be involved. Some people don't even know what a care plan is.
When people are not feeling good, they need support to be involved.'

People were afraid that when their assessments were checked they might stop getting services, or the services they would get would not be the right ones.

One service user said it was hard to get hold of people and services on the phone, and that might stop people from trying to use services.

Service users also said that getting help from duty was different.

'The delay in [getting] services is adding to my stress levels.'

If something is not available as a service it can make service users feel very uncomfortable and at risk.

'It's devastating.'

'The system assumes you have friends and relatives who will drop everything to help. This is not always the case.'

A person's needs were checked in a way that was not caring and not personal.

'Last review I had was one minute over the phone. Social workers should come to your home and listen to what you have to say.'

Many service users said it is hard to get a service. One mental health service user said they could not get help even after trying to kill themselves.

Service users said that not getting the help needed can make them feel like taking drugs and drinking, and end up with even more problems.

One group of black mental health service users generally thought that the social care services they got were good and helpful.

There were some things that were not so good, and this showed some of the bigger problems for black mental health service users.

'Let's not forget how much they drug us up.'
Service users said there were services that had the same problems again and again.

'You have to do everything yourself. It is a nightmare trying to get a wheelchair repaired.'

There's a lack of understanding towards self-funders. Even though we have to pay for care, we still need help to sort it out.

Service users don't get enough help

Many service users said that the help they get was just not enough.

'One hour shopping and one hour's cleaning per week is all I get.'

One group said there was no service for adults in between young people and older people. They said that the only choice was a day centre or nothing.

'[Social services]…. they visit you and then forget you.'

Because people working in social care changed jobs a lot, service users often had to tell people their needs again and again.

Problems with agency workers

There are problems when agencies are used to give care services. Not all the people working at agencies are good at their job.

Services are sometimes bought from an agency for all service users, and that doesn't work for certain service user groups.

Agencies seem to care about making money more than helping service users.

If service users said the agencies were not doing their job, the local authority did not want to do anything because they did not want the agency to stop giving all their services.
'Care agencies just employ anybody - they are not interested, only want to make money.'

'Any Tom, Dick or Harry coming into the house. You don't know who they are.'

When local authorities started working with agencies, people thought it would give service users more choices. But service users say that getting services from an agency also means problems.

Some people had good things to say about agencies.

'Using an agency that gives carers for three periods, so that there is continuity [has been a good thing].'

It's hard to get good help

Service users said that you had to be very strong and keep asking for the services you want. This is not fair and means that not everyone gets the same services.

'Any assistance you need, you have to fight for it.'

'It's difficult to ask if a police check has been done. You need to know who to complain to.'

'We get good support from a GP - we helped get direct payments for a carer - but we are a group that knows about things. Others don't know.'

Equipment took a long time to come. People working to help service users get better from an accident or disability were not always very good:

'I know more about my condition than they do.'

Service users said people still thought of disabled people as a problem, rather than seeing how the community treated disabled people as a problem.

'Professionals don't understand the social model of disability.'

One person said that she paid for personal care but it should be free.
Service users felt that they should get the help they needed, and not only get the help that there was money for.

Not knowing what you will get is a problem

People get social care when they need help most in their lives. Social care is very personal and private. It's very important to people's lives.

But sometimes, service users can't be sure that they will get the help they need every time they need it.

Sometimes service users don't know if the help will be good, or if they will get help at all.

One service user said that the way different social workers think can be very different, and this means service users could get different kinds of help.

'It would be nice not to have to worry about there being more cuts [less money] all the time.'

'Some workers are rare pearls, but there could be a change of staff that upsets all that.'

Too much paperwork is a problem

Bureaucracy is when an organisation works by a lot of rules rather than using common sense.

These organisations work with a lot of paperwork and usually write rather than talk to each other. Everything is done the same way.

For the last 25 years, the government has said it does not want bureaucracy to be a problem.

But for service users it is still a big problem.

'Too much paper goes round and round.'

'There's too much paperwork and not enough hands on.'

One group said that a user-run service in their area was much better and easier to use.
Service users say bureaucracy takes control away from them.

Papers and information get lost, and what service users say is different than what care workers write down.

'Not having to fill out big forms and be made to feel like beggars.'

Bureaucracy costs money and service users see this money being wasted when it could have been spent on services. Service users said the bureaucracy has to stop.

Service users said that services must stop doing small unimportant things that are done only to make services look like they are doing something.

Services that are not the same and not fair

Service users had a lot to say about how services were different from one council to another.

They were also unhappy that they could not go back to getting services they had in the past.

More local authorities were using agencies to give services, and were not thinking about the importance of each service user’s need and how each service user works with a service provider.

People wanted to get the same service wherever they were.

'Some [service users] can go to the football and the pub. Why can some go and not others?'

Some service user groups had special worries. For example, mental health service users are worried about a new law.

Some groups had a worse time with social care because they use more than one service.

People working in social care did not know how to work with some service user groups.

'I have a label of multi-disability person, which means I have
"lots of things wrong" with me and they don't know which box to put me in.'

'There are problems of transition, for example, moving from child to adult services and from adult to older people's services. There are problems around having to start with a new set of staff.'

There are still some groups having a lot of difficulties getting important services and help.

Some groups only get a few services and do not get a lot of choice.

**Services that don't change**

Services are not quite right for people's lives.

Service users said that getting care was so strict and controlled that they did not feel like they were doing things themselves or that they were in charge.

Half the people in one group that used day centres thought that day centres were kept away from other people and the community.

In another group, service users thought day centres were good but said services and activities were being stopped to save money.

Many service users do not have the right help. Things are not changed to be better.

People are also worried that information was not kept private when working with people doing their learning.

'Bring back old services like home help.'

**Different departments not working well together**

Health and social services do not work well together.

People cannot use direct payments to pay for health services. This was unfair for service users with different needs.
Different departments did not talk to each other.

'I have social workers, occupational therapists, district nurses and others and they never talk to each other. Every time a different worker comes, they ask me what's wrong with me. I say, "haven't the other people told you?" and they say "we don't do that". A friend suggested I throw a Christmas party for them all, get them all here and make them talk to each other.'

Services are different for each disability, for example, people having trouble hearing, or who can't see. But sometimes the needs of these people are the same.

Service users are worried about the new plan for health and social care to work together. Some felt that it might be ok in the future, but are worried that there will be new problems when this starts.

There are also worries that working together will mean that the medical and health people will take over.

Service users are worried the medical people will make everyone think that people with disabilities are the problem.

Problems can happen when one department stops working and the other department starts, but it's not very clear exactly where this takes place.

'[There needs to be] more confidentiality between the professions.'

'[There is] poor communication between services.'

'[There need to be] better systems so you don't have to keep repeating things to different people in different parts of the service.'

Things service users are afraid of

'People are scared at having services withdrawn if they are seen to be stroppy.'

Service users are afraid that they may be sent to care homes and hospitals.
Being afraid makes service users not want to speak up for what they want and need.

Being afraid makes service users thankful for anything they get, rather than asking for what they really need.

Personal assistance services need to be checked to make sure disabled people are not left without any help. For some service users this is something they are really afraid of or has happened.

A lot of service users said they feel bad about asking for a service and did not feel very confident about having to ask.

There is not a lot of understanding of how service users can feel bad when asking for services.

Service users should be able to speak up and say what they want. Many service users thought that social care made it hard for them to do this.

The service users in this consultation said service users really needed to stand up for themselves and be stronger.

About people working in social care

There was a lot of talk about how good the people working in social care were.

There were some good examples of people working in social care.

Service users thought that the people working in social care were not always as good as they could be because they do not get paid a lot of money.

Workers had been rude to service users.

One group said that people working in social care do not seem to care about the way things are.

'They look at you as though you are stupid.'

'Workers can be patronizing.'

'We should be treated on equal terms, not talked down to.'
Service users said some people working in social care talk to service users as if they did not understand anything.

Some people working in social care talk to service users in a way that takes control away from them. This was something that all service users did not like about social care.

'The people who come to you just see you as a number. They've got 12 to 14 people to see in the morning so it's like you're on a conveyer belt. People do not get quality of life. They lose their privacy and their dignity.'

'I feel like I could die and it wouldn't matter. The people don't know you. They don't care about you.'

In one group, a gay service user said she found it hard to get a care worker who accepted her and she would have been happier with a gay carer.

What is important about people working in social care

In one group, service users said that they thought many care workers were good and did an important job for little money.

'Bad ones stick out like a sore thumb.'

Service users liked workers who helped people to do things for themselves.

Having a manager from a certain service working with you also helped to get that service.

One group thought that social workers were getting better and that social care was also getting better.

Another service user said how much of a difference it can be having a good social care worker and having the same social worker all the time.
How to make things better in social care

These are the ideas that service users had for making social care better.

The words people use

The words people in social care use need to change. Many service users don't like the word "care".

If services were going to be more what service users wanted then the words in social care need to change as well. Instead of "care", words like "personal assistance" should be used. "Care" sounded like the person couldn't do things. "Care" was not a helpful word.

'Care is what people who love you do.'

'The Government treats us as scroungers.'

Service users say they are experts or people with a lot of experience. This needs to be said and recognised by people working in social care.

'We are hidden away.'

Training

Many service users had thought a lot about training. Service users think training is an important way of making things better.

People in the groups talked a lot about what was the most important thing for people to get training on.

They talked about if it was better if someone didn't have training, because then they did not have all these wrong ideas of how things should be.

People talked about if people in social care were getting the right kind of training.

'Training doesn't necessarily mean they are good.'
'Relevant training is needed.'

'I get good workers who are not trained. Trained workers think they know it all and boss you around.'

Training should be given to make sure that people working in social care have the right basic skills and know the most important things to do their job.

Social care needs to be a job that people study to do.

Workers need to get help to think of ways of helping people in different ways, and to use their own mind and ideas.

Personal assistants are taught to go shopping for a service user but not how to get the service user to join in.

Training should make sure that workers treat a service user as one person, not a group of people.

If service users were part of training then a lot more change would happen.

Making things easy

Service users in one group said it was very hard to start getting help from social services and that it could put people off.

'It's too stressful. A real barrier. I just want to be left alone to get on with it.'

'We need easier to use services.'

Service users wanted easier ways to say when something was wrong.

Service users also thought that more people should know about the different choices that service users could make.

Benefits

There are too many different benefits.

The benefits are hard to understand and hard to tell apart. Because of this, benefits don't end up being very helpful.
'It gets people into trouble, can lead to financial mismanagement and is open to abuse.'

Instead of lots of workers giving advice, it might be better to have an easy way of getting benefits.

If service users are always on benefits they don't feel good.

Service users getting benefits for a long time can get stressed and start to feel bad about themselves.

'Health improvement is penalised in terms of benefit receipt that encourages a state of learnt dependency.'

**People working in social care and money for social care**

Services are often bad because there is not enough time, people and money to give good social care.

Service users feel that government money that is supposed to be for social care is not always used for social care, and if that money was needed for other government things, the money was taken away from social care.

One group said that services were given only if there was money for it, not because someone needed it.

'We feel patronised by this.'

One service user said that there was not enough work looking at how many needs were not getting help.

Again, people said that care workers were paid so little that they did not feel they had to do a good job.

Care workers had a lot of work to do for the little money they get. Service users realised the hard job care workers do.

'In a job which requires 10 people, they have 3 people to do it.'

'They could employ more workers and not overload the ones they have - and pay them more. There should also be room for workers to deal with stress.'
'There should be enough social workers to go round and they should pay them more if they need to be paid more to recruit.'

'We want them to stay on the job.'

Most service users felt that none of the problems with people working in social care would change if the workers still got paid little money and did not feel their job was important.

Because there was not enough money for services, service users had to pay for some services. This stopped service users from getting the help they needed to live well and do things for themselves like other people in the community.

'We need a fairer system - get away from means testing.'

'Community care charges, cannot pay them.'

One group said that the more service users had to pay for services, the less social care was able to help, and that this was not fair

Everyone said that if any real changes were going to be made to social care, there needed to be enough money and people to make these changes happen.
How service users would like social care to be

These are the dreams, plans and ideas that service users would like to see being used as a way to plan how social care should be in the future.

Service users had a lot of ideas about how social care should be in the future. They could think of many ways social care should be instead of the way it is now.

Service users said social care in the future should help them lead good lives with plenty of choices:

'It is getting assistance from the community as opposed to family and friends.'

'It enables people to live a more fulfilling life and to be independent in society.'

'Assistance to lead your life in the way that you choose.'

'Whatever help is needed is provided in an understanding manner.'

'Choice and control.'

From personal to social care

One group explained the difference between "personal" and "social" care.

Personal care is getting basic help, and social care is getting help to be part of the community and having a full life.

'It's the need for continuing support - not medical need'.

For many people social care still seems like personal care:

'Currently it is like house arrest.'

'I have got to stay in the house. I should be able to get out and lead a normal life.'
"I've got to fight to be able to go to church!"

Service users see real social care as something very different:

"It means you can be part of the community. Means you don't have to live in a hospital."

"[It's] not just personal care. It's help with social life and so on."

"[It] means having communication support which means having equal access."

Service users feel that the first thing to do to make social care better is to do the things that social care workers already know will make things better. If this is not done first, then new ideas are not going to work.

**Things that are important to service users**

Service users joining in

Service users are starting to be asked to say how services should be.

This is needed in many parts of social care. But there are problems when users join in.

Sometimes, service users are asked for their ideas, just to show that services are asking. But nothing is done with service users’ ideas, and the departments asking do not really want to listen.

"User involvement is very difficult. You can't get your say because there are so many professionals [in the way]."

Service users should always be asked what they think.

"It should not be simply a rubber stamping process."

"If you want genuine involvement for people, you have to be prepared to pay for it."

"We need more opportunities to talk like this."
One group said that service users saying what they think would make services better for different service users.

If service users join in then it should be all service users, not just the same voices that always speak up.

There has to be enough money to let service users be a part of social care in a good way.

Many service users thought that service users should be paid for the experience and advice they can give to social care.

This would be good for social care and it would let service users have a chance at other work in social care.

'[We need] more service users working in service provision.'

Service users checking how services are run is the only real way to make sure services are as good as they can be.

'[We] want to know more about where the money is spent.'

'User involvement is the only way to get accountability.'

'Users and the public have to have more say.'

'There needs to be some kind of monitoring panel to look at the way people are doing their social work.'

'You need monitoring to ensure you are getting the help you need.'

'We need more advocacy.'

One idea was to have a group of service users that checked different social care work.

Another group said that social care services would know if they were good if they listened to service users.

Service users said they should be taking part in all parts of planning, running and giving a service.

It should be real taking part, not just something that looks like service users are taking part.
Service users also need to join in when policies and government ideas are planned.

There should be local groups that work with the skill and experience of service users to make sure this happens.

'There needs to be more disabled people doing jobs of responsibility because they will understand what it is like to be a disabled person.'

There needs to be more service users joining in.

Most service users said that the best way to get service users to take part was to have more people working with local service user groups.

The government needs to see that service users are very important for making services better.

The government needs to put money and work into making local user groups strong.

A lot of service use groups are worried about how little money they get from the government for the work they are trying to do.

There was a lot of talk about where money to run service user groups should come from.

Some service users thought it should come from the government.

Other service users thought it should come from local authorities and health trusts.

Everyone said that it was important that there was enough money to run service user groups.

Service users as part of the whole change

Having service users join in is part of changing the whole way social care works. Changing social care will work best if service users take part and continue to be a part.

'Social care needs to be more inclusive of us.'

'We are the experts on disability.'
'Social care needs to be developed in an inclusive manner.'

'[We] need a national advisory committee of service users.'

Service users saying what makes a good service

Service users said it was very important to say if a service was good enough. But for a "good service" to really mean something, service users must be a part of saying it's good.

A service could not be good if someone who used it did not think it was good.

Service users had seen services being checked using paperwork, questions and rules.

There are things that stop service users from really being a part of saying a service is good enough.

A good enough choice

The government said it is important for service users to have a choice of services. In social care this means service users can choose services from:

- local authorities
- voluntary organisations
- private service providers.

But service users have had problems with all of these different service providers.

Service users think choice should mean:

- how much control a service user can have over a service
- if they can use a service
- how they can get a service.

Only a few service users used direct payments, but they said direct payments made a real difference and gave them a lot of choice.

Direct payments give service users choice, in the way service users want choice.
All different but treated fairly

It is very important that everyone is treated fairly and the same when giving services.

Services should also think about helping service users from different countries and religions.

'We are all equals. We still have free will.'

'People should be on the same level. Not them up there and us down here.'

'Equal but individual.'

'We want to be treated as equals.'

'Everyone should be treated equally.'

'Too many people take no notice of the Disability Discrimination Act especially when it comes to communication.'

Service providers should not think of a service user as good, bad or better than another person.

People are different and service providers should be ok with this.

There has been some work done on service users from different countries but there is more to do.

Services and people working in social care should see and understand that everyone is different.

'What I like about social care is that my key worker, my housing officer is from my background, because once upon a time, you couldn't really get that.'

Some areas are not good at treating everyone the same and treating people fairly.

One organisation had got money for helping black and minority ethnic communities to get direct payments. This was a good thing.

One service user did some work with refugees and said refugees needed special help.
Service users have rights too

Service users talked a lot about their rights, more than they talked about their needs.

A right is something that all people should have or how all people should be treated.

Service users also have rights and things they should get by law.

Service users have responsibilities but a lot of people forget this.

'People should have rights. People pay in taxes and don't get support.'

A service user in one group said that no services were being given from the idea that service users had rights.

Social care is about society

For services users, the good thing about social care is that it is about social things, like where someone lives and the people around them.

At the moment, social care is too much about what it costs to help someone. Instead, social care should be about letting a service user be as good as they can be, to do all they can and get the best life they can.

If a service user can do something, they are seen as needing less help. But the service user may need help, and can do a lot more.

People working in social care should think about social models from the time that they do their first assessment with a service user.

A social model is a way of looking at something.

The social model of disability sees that people with disabilities are disabled by things in society. This may be how people think, how to get into a building, or how to read information.
The social model sees that people with disabilities have the same wants and needs as people who do not have disabilities.

One idea was for a team to do assessments thinking about the social model.

This had worked well in one place, but then was stopped. In this area, the assessment forms still have some social model parts and service users think this is important.

The way an assessment is done needs to be the same for all service users, and it needs to look at everything they need.

Independent living

Disabled people started the idea of independent living. It has been very important to many disabled people.

Everyone at the consultations said independent living was important.

People who were not disabled said it was important that all service users got good help that was right for them, to help them live their own lives as best they could and as part of the community.

Service users talked about quality of life and about having a good life. Service users wanted a good life in the way they saw life being good.

More people using direct payments

Many service users think that direct payments are one of the very good new social care ideas and are very important for independent living.

Service users who got direct payments, or who were about to get direct payments, usually said good things about it.

'It's given my life back. Now I control who's helping me and when they come in. It's also given me a social life and I can do things that I want to do.'
'I have had my own personal assistants for 10 years. You get a better standard of care.'

'When you employ your own personal assistants, you have more say and know what you are going to get - when.'

'Having direct payments has meant having a better social life, getting out. All this has boosted [my] self esteem.'

'With direct payments I can use hours for shopping which I couldn't before. This is a great improvement.'

'Having a good personal assistant stops you feeling isolated.'

'The move should be to self-assessment and direct payments.'

But one group said that there are still a lot of big problems trying to get direct payments.

'They need to be more widely available.'

'Everyone should have the opportunity to have direct payments.'

'I waited two years to get direct payments.'

'There was a long wait to get assessment.'

'Things are very good when they are done, but you have all the hassle of getting them, so it's the bit in between that is so nerve racking. But when they put all the bits together, it all ends well!'

There are still big problems for service users getting personal assistants who have had good training.

'Staff are not trained properly. There are problems with agency staff.'

'There are problems of getting personal assistants (PA's) trained when you are on direct payments - who supports you while they are being trained? Who pays?'

It is very important that there is more information on direct payments so many people will know about them.

'The Minister needs to put his money where his mouth is.'
Direct payments need to be made easier to work out. This could be done by using service user groups to help people choose services.

Service users should be able to use direct payments to buy health care services.

For direct payments to work, there needs to be a good way of working with service user groups in each area.

Helping service user groups in a smart way

In one area, services were set and run by a local disabled people's organisation. This meant that people were not talked down to by people working in social care.

Service users think user-led services are very good.

A centre for independent living that was run by users in an area was used a lot.

Service users liked getting advice from other service users.

Services that are run by user groups are better than services that are too hard to work with.

Service users wanted more services in the community. They also wanted more service users giving services.

'The best people to help us is us.'

Services should start by listening to what service users wanted.

Services should work towards people being able to do things without help.

There should be more Independent Living Centres and more service users should be able to use these centres.

Listening to service users

More than anything, service users want people to listen to what they needed.

Almost all the groups said it was very important that social
care workers listened to service users.

Many service users said that listening could mean the difference between them getting good or bad help and services.

One person spoke about a social worker who listened and was helpful:

'Very nice, not like other social workers. She did everything she could.'

Service users said people working in social care had to know how to talk to people, how to act and be with people. This would help workers to work with service users to fix problems.

'I'd like the social worker to listen to what my needs are so that they can work with you rather than telling you what to do.'

Listening is important for all people working in social care, from the people who work with service users to the politicians who make decisions.

People also had to understand what they listen to.

Listening is very important if government ideas are going to get better and social care is going to get better.

If someone working in social care was a good listener, then they would probably also be kind, have common sense and respect service users.

Social care that really is for people

People are not used to thinking about service users as people who can do any good for the community.

There are a lot of things that stop service users taking part in the community, and these are not their fault. But these things stop service users from doing much more than getting benefits.

The way benefits and social care is given needs to change so that service users can do what they dream of and be more a part of the community.
There has to be changes so that people working in social care look at service users as people.

Service users think it is very important that they are listened to.

Social care is run by plans and money, but it should not be. It should be run by what people need.

Social care would be doing this if it listened to service users.

'They should work around the person and their carers and not the other way round, which is what happens a lot of the time. People should be at the centre and be treated individually. I waited 10 years to get a really decent social worker, and what was good about her was that she was the first one to say to me we are going to sit down and do the care plan and I want you to be involved.'

'Treat people as one [unique person] and have respect for each person.'

'Social care workers should be able to fine tune each care package to that person's needs.'

One service user said she had worked out her own service level agreement with the local authority and was very happy with the services that she got.

'Whatever care is needed [should be] provided in an understanding manner.'

'We need more information, more openness - less force.'

Two service users said it was important to think about the basic things a service user needs but also what they want.

They said service users should be able to have what they need and what they want.

'You need to look at desires as well as basic needs - more pleasure as well as care.'

'You have to say "I need..." to get anything, not "I would like..." or else you end up getting nothing.'

Service users need to be the ones who decide how services are given.
Social care needs to be able to change a little so service users can easily join in planning.

It might be a good idea to make it clear what service users can and can't get. This would be the start of a simple but fair way of giving services.

Another way to help services to change a little is by looking at local authority plans for spending money.

Money could also be saved if people working as personal carers could pay less tax to the government.

Service users also wanted social care to think about everything in a person's life, for example if a service user was religious or was gay.

Service users said that social care and services need to be more holistic.

Holistic means looking at all the things that make a person, and not just looking at parts of a person.

If services looked at service users as whole people, then service users could join in the community more.

'Need to look at the whole person.'

'We don't so much need their help. We need them to help us help ourselves.'

It is important that services work with other departments and organisations, for example: health, houses, education, training, leisure and activities.

Social care need to change to be what any one service user needed.

Social care has to work the same way for all service users. Instead, getting a service can be different if you live in different places.

Services might not be right for one person, and sometimes a person might even be worse off because of services.

Service users wanted people working in social care to notice the little but important things and change as these little things needed.
An example is that a Muslim service user might be able to get Halal food.

Money should not be spent on things that are only a quick service and not something a service user would want.

There needs to be more information on services.

People working in social care need to talk to service users more about things.

People working in social care should write back if they are sent a letter. One service user said that social services promised her a letter, but:

'It went to Timbuktu and didn't come to my house.'

Service users in one group said they were worried about the way that social workers and other social care staff were always thinking about things that might go wrong, and that they were scared of making a mistake.

Workers didn't think of a service user's rights and needs, but thought about making sure they, the worker, did not get into trouble.

'Risk is part of life.'

'They need to accept that they are there to help us. There should be less concern about risk.'

People working in social care need to listen more and change what they do as needed and asked.

The things that make a good person or good service are different for a service user and for a person working in social care.

The important things that make a good service or worker have been said many times by service users.

'They should have knowledge of the background of the people they work with.'

'Developing trust is essential. If you don't like their personality, none of those skills [they may have] are going to work.'
'They need to be good all-rounders.'

'They need to be more supportive - help people work out solutions.'

'[They need] a good sense of humour!,'

'Respect' is the major thing in the provision of sensitive social care.'

'A understanding and caring attitude, a bit more of their time, more information of what you're entitled to.'

'They should be able to help with form filling in and housing.'

'What they are entering is the caring profession and they should be very tolerant and patient.'

'More gentle and less forceful.'

'Local, honest and reliable [staff].'

'Ve should set the agenda [say what needs doing].'  

'Compassion'

Service users should be able to respect people working in social care just as people working in social care should respect service users.

Service users said that people working in social care needed to have the right training to do the job.

People working in social care need to be sensitive and they need to be able to see the things that make a difference to service users.

This will help them work with the big problems and be a real help.

What one service user thinks is helpful could be too much for another, so people working in social care need to be able to see the differences.

Service users said people working in social care should think that each person they work with is different and might want different things to help them.
Getting better help from better information

Service users don't always know what information and services there are and can't make a good choice.

There needs to be more information on what choices there are, and everyone should know about this. This information could be on the radio, tv or internet.

'We need information.'

'Better access - 24 hour helpline to get services.'

'Being able to reach workers by phone, better communication and better information about services and what help is available.'

'They ask us what we want, but we don't know what we can ask for.'

Everyone said it was very hard to live without help because the forms to get money to live are long and difficult to fill out.

It's hard to find somewhere to live because there is not enough housing which is good for a disabled person to live in.

It takes a long time to get the money to make special changes to a house for a disabled person.

Social care working with everything

Service users said that to know what social care meant to them, you also had to think about people's lives, and who they were and what they did outside of being a service user.

Social care needs to let service users be people in the community as much as possible. This would mean new ways to get help and new ways of working would be needed.

'We need to break down barriers, build bridges.'

'As single parents we need help with child care so we can go back into education. We need crèche available in the evening. We need support.'
'Social care needs to link in with other services like leisure services and education to support people to do the activities they want to.'

'We need a good support network.'

'Preventative measures.'

'[Accessible] transport.'

'Show us on television leading normal lives.'

If some things were better in the community, like how service users get around using buses and trains, then service users would need less help from social care.

Social care being important

Service users think that social care does not get as much money as the NHS. They think that social care is not seen as important as the NHS.

Social care does not seem to have as many people working in it and it's not good for people to work in social care.

Social care needs to be seen as important and the work people does needs to be seen as important.

Social care and the way services, help and equipment are given needs to be done in a way that makes service users feel good about themselves.

Are you being serious?

Service users wanted things they said to get back to the government. They really want the government to listen to
what they say.

What people with learning difficulties say about social care

This part is what people with learning disabilities said about social care. They talked about how services are now and how they would like them to be. They also said what things would make social care better.

What makes things better in social care

Social care is good if there are good people working to help people with learning difficulties.

People working with learning difficulties are good for the job if they:

- listen
- treat people with respect
- help people with learning difficulties do things for themselves
- say that it's okay for people to be themselves.

The things that make social care good for people with learning difficulties are:

- good people working in social care
- being listened to
- being treated with respect
- being able to do things themselves
- good training for people working in social care
- money for services to help people with learning disabilities
- service users checking if a service is good or not
- different services for people to choose from
- chances to get real jobs and training.
How people with learning difficulties would like social care to be in the future

In the future, service users would like to:

- get the help they want
- have real chances and choices to get direct payments
- be part of the community
- have help to live on their own and to live the life they want
- have the same choices as other people
- be treated as equals
- have rights.

How services are now for people with learning difficulties

Service users don't know if people working in social care are good enough and will do the things they say they will do.

Services are in charge of service users and it is very hard for people with learning difficulties to speak up against this.

To make things better for the future, the problems there are now have to be clear and understood.

Service users and service providers have different ideas on what is a good service.

It's hard for people with learning difficulties to speak up if services are not what they want.

Service users want to be in charge of their lives, but social care services try to be in charge of service users' lives.

People with learning difficulties find it hard to get the help they want from social care services.

Social care workers can be too bossy and too nosy instead of being helpful.
'We are here and social care is over there, who is making the decisions? They are saying totally different things than what we are.'

One woman felt she did not get any help from her social workers when she was getting bullied by a neighbour about her race. She and her husband had to move home because of it.

Social care can help:

'It's good to have people like social services and it can help, but it's like them and us who are trying to control our lives.'

But when service users need help:

'When it comes to say what you want, they get weak. They get so weak when we tell them what's going on, their levels go right down. We are the ones telling them what to do and they get so low down.'

One person said their social worker was:

'a nightmare, she put me in a residential home, her decision, she put me there. She made it all for me; she said I was severely disabled. It was the wrong place for me.'

'Service providers and staff are shocked that we are allowed to speak up. They should help us. Staff don't always want to change or want us to be independent.'

About people working in social care

The way a person in social care works can mean a service user gets good or bad care.

Some people working in social care are mean and bullying. They can be scary and rude and not treat people very well.

It is important to treat service users with respect.

Service users want all people working in social care to really care, and to do what they say.

One person said her social worker doesn't tell her what time she is coming - or if she does then she is late for appointments.
She also said the social worker wants to know things that are not her business.

She said the social worker is: 'bossy and getting annoyed with us'.

She also said the social worker is 'scary' and 'two faced' because she says one thing and does another.

She would be nervous about trying to get the social worker changed.

Other people said:

'They treat you badly and talk behind your back. They treat you like you are dirt and they don't give you a chance to do things.'

'Or a chance to say anything.'

'Bad [workers] think you are stupid and can't do things. They don't understand you.'

'My support worker is basically an arsehole. He sometimes, on Friday and Saturday, he makes fun of me and calls me names because I dress up as a woman. Sometimes I cry.'

'I've had bad experience. They used to hit you across the head [in one residential home for mental health service users].' 

What service users think makes a good social care worker

A good social care worker is one who is:

- helpful
- treats people well
- someone who helps service users speak up and stand up for themselves.

People with learning difficulties said a lot about what they don't like, and about what things happen now, to show how they would like things to be.

'[They should] treat you with respect, more independence, listen to us.'
'[Workers] should behave themselves, come when you need help and not be bossy.'

'Workers should be there when we need them and keep appointments when we want them.'

'Workers should be helpful and polite.'

'I'd like them to treat us better and understand us better in the future and be nice to us.'

'[They should] Understand what people are saying to them… and be kind and give support…'

'…when you need it.'

'[Workers] should not treat people like children.'

People with learning difficulties also talked about good things that had happened to show that they would like this to happen more.

One person liked the work experience they did in a shop:

'I got support. I enjoy working with support and a key worker. [The key worker was] very supportive, helping with forms and supporting me with going to different places and hearing about benefits.'

‘God bless our support workers [advocates and advocacy workers]. You just go to social work for problems.’

One woman talked about a group for black people with learning difficulties she was part of. She said it helped her a lot because it was:

[It's about] 'people getting together, it's a life line, need to get into certain groups that give you hope, need to get into a group where you are comfortable because you need that or you crack up…..For me the majority are all white. They don't know about us. [They] can't reach where we are.’

She said a group called People First helped her too. She also said: '[getting] counselling for the first time was really nice.'

It was also important for people with learning difficulties to get:'Free holidays, where you want to go' and 'bus passes'.
Not everyone could think of something they liked about social care. When one man was asked, by his supporter, if there was anything he liked about social care he answered:

'Not really.'

Several people had social care workers they really liked. Good workers can make a big difference and that is why they are so important. But they need to be good workers in the way that people with learning difficulties think.

One person, speaking about her own social worker who she really liked said her:

'Social worker….sorts everything out when you have problems.'

Some people talked about how they liked one particular project to help people with learning difficulties get a job, because the manager was good and they liked her.

Another woman had just got her own flat with her husband. She was very pleased with the help she was getting from the social care worker who lived in a flat "downstairs" from her. She said: 'She is nice. We can go round to her flat if we have a problem.'

Good workers need to have good ways of talking to people and think that service users are important.

Good workers need to help service users to get their rights and the things they should have.

People with learning difficulties want to be seen and liked for who they are.

People with learning difficulties give each other help.

This is how one person said good social care workers should be:

'They have to be radical, have to be real and get to the point, don't take no rubbish.'

People said that for social care workers to be good at their job they needed to have things that made them good people as well as good professionals. Because of this, one man said he had never had a 'good' social care worker.
However he said a good social care worker should be:

'Nice, funny…someone I can talk to…and a good friend.'

'Support worker needs to know the rights of the person with learning difficulties. [good support workers] gave them [people with learning difficulties] their rights as human beings.'

'[Good support workers]…let you know who you are and see you…are your friend. Not what they are paid to do, someone who knows a person well.'

'We need people around us who want us for ourselves.'

'Make sure the person's got a good attitude, sense of humour, good eye contact.'

This man said the worker should think about what the person with learning difficulties would like to do. He also said a good support worker should be good at listening, be good at helping people and sorting things out.

Someone said that a good support worker should be patient and not get cross if the person with learning difficulties took time understanding things.

'[Good support workers] support you to do what you want.'

'[Good support workers] don't take over.'

'[A good worker is] understanding - they understand, listen, [are] kind, respectful, help us with problems.'

One woman said that good support workers need experience of doing 'work for a long time with people with learning difficulties'.

She said workers should: 'Go to college to get different skills for working with people with learning difficulties'.

Someone said that workers: 'Need to know how to work with people like us'.

Some people talked about how it was not only paid workers that helped people with learning difficulties, and that people with learning difficulties helped each other. This is important for people.
One person talked about how he had supported someone else in the group when she was going through 'hell'.

He said that he was now a 'mentor', or someone who gives advice and experience to help. He told us how important mentoring is and he said:

'People who are very close and [have] been there all the way through help a person find a true identity for themselves [they] look at the person inside you. [It] helps you carry on.'

**How to make things better in social care**

It is important that there is good training for those people working in social care who don't treat service users nicely.

Service users should be helped so they can train staff and check services.

Workers that people with learning difficulties think are good could train other workers.

Service users want safe ways to say if a service or worker is good or bad.

Some people with learning difficulties said that service users should train people working in social care.

'I don't think social services respect the identity of the person and feel they don't fit into the community because of how that person is. They need training on how to talk to people, respecting that person without offending them. They need to think about how they are in themselves.'

One service user said that they would like the good people working in social care to train others. Service users could choose who these good people were. This could help people working in social care to think better of people with learning difficulties.

'[It is] important to look after yourself as a black person, making sure some people aren't racist against you.'

'People should be trained to understand, maybe people who have different needs should do the training.'
The things that are important to a service user should be the things that people working in social care are checked by.

For example, if people working in social care needed to be checked to see if they are good at their job or good for a promotion, then the things that are important to a service user should be looked at.

This could also help when services and departments are checked to see if they are good enough.

One service user said that the 'tick list' did not look at how people working in social care did things and how they treated other people. Instead they looked at 'performance, money, careers' and not 'working to us' [service users].

'Inspectors - service users would do inspection.'

One idea was that people with learning difficulties have a form that let them say what they thought was wrong about the services they for.

A service user said that if a person working in social care did something wrong then they should have to explain that to a service user.

People with learning difficulties could give social care workers a mark or score to say how good they are at their job.

Another idea was that workers wear name badges so that you know who they are.

People with learning difficulties should be able to say what they think about services and people working in social care without them knowing who said what.

It would also be helpful to go out working with social care workers to watch them work.

People with learning difficulties should write down if workers were late for meetings with them.

**Workers and money**

A lot of people in the consultation said that there was not enough money for services.
They felt there was not enough money for paid workers so they did a bad job.

They said that service users doing work experience and training did not get paid enough, or sometimes anything at all, and should at least get minimum wage.

'There are] lots of cuts for ...disabled people....lots of discrimination.'

'They are short staffed so they fling people with no skills into jobs, everything is money.'

'What they give you [on work training] is peanuts money. They pretend you have got a real job, but it's not. The government say you must do this you must do that but only for a year then back on the scrap heap. [They] need to think about what you want to do with your life.'

'People with learning difficulties should get paid. If it wasn't for people with learning difficulties [people who are working services for people with learning difficulties] wouldn't get their mortgage money paid.'

Things to make better for the future

Service users think there should still be things like day centres and colleges because people can meet their friends.

Racism in day centres needs to stop.

There are not enough interesting things to do in day centres and colleges.

There needs to be more choices.

There needs to be more people working in social care to help people with learning difficulties get real jobs, or to work helping others.

Good day services are important. Someone said this about a day centre:

'A lot of my friends used to go to [a day centre] to meet friends because they were fed up with seeing families and carers 24/7. That was really positive because they could go to [the day centre].'
Another woman liked the catering work training they had done because it was friendly.

'I can make friends and have and join in conversation.'

She also liked doing gardening. She said she liked: 'soil in pots, flowers, gardening'.

But people's experience of social services and college is often bad. Another man said he didn't like a social services day centre he went to.

'I didn't like it that much because it was like, I felt bored and really terrible, racist names, they call you golliwog...The staff didn't want to know...I lost my temper...I didn't get any help at all... so angry and helpless, I didn't go back there, I felt let down by the staff.'

'College, bloody boring, still going.'

Many service users said that there was not much to do at their day centre and that they would like to go out on more trips in the summer.

Another service user said that college closes for too long over the summer and there is not much else happening.

One group talked about an old day centre that was on an industrial estate. Service users thought it was wrong that it was on an industrial estate away from the shops and people.

One service user said that the best thing that they ever did was to close this day centre down.

One woman said that people want the chance to work but some people will always want day centres.

She said ‘we want choices’. She also said that instead of going to college for ‘years and years’, people with learning difficulties want to be helped to work.

Someone talked about how they want to help other service users and how she was stopped from giving help:

'Ve can help them. I used to work…. [in a home for elderly people]. They let me help with some other people and some didn't give us a chance to do it.'
Someone else said they wanted to move on and do other things like helping people to speak up and raising funds for charity.

Another person wanted to work helping disabled people to get their shopping.

One person wanted to help people who were affected by the war in Iraq.

Someone else said she would like to raise money for people in Africa.

People would need the right help to do the work they want to do in the future, to give something back to the community.

What people with learning difficulties want for the future

Good social care is about giving service users what they want.

There is still not enough choice of things to do.

Not enough people with learning difficulties are getting direct payments. This must change.

One person said that good services are those that give each person what they want.

'When there is a crisis in our lives [we] always have to wait. It would be good if I had a social worker, not just a duty social worker, so [I] wouldn't have to repeat myself again.'

'If they don't listen to you, you are on your own again. They should know a person's feelings, [if] they don't respect your feelings how are they going to make sure you get the right help?'

Another man said they wanted to move out of their council flat because there is a lot of crime in the area. He said: 'People don't clean up after themselves'.

He wants help to find another place to live but is not getting it. He talked about how his support worker didn't listen to what he wanted.
He also said that lots of people with learning difficulties would like direct payments, and that people are, as he put it:

'Fighting and fighting and not getting anywhere [with getting direct payments].'

He said he would like to choose his own support worker.

Another person in a different group said that direct payments might help because you can choose staff and get up when you like and go to bed when you like and have more choice and control.

Talking about social care services one participant said:

'They don't take people with hidden disabilities into account'.
'I've got autism; sometimes I feel they don't do a lot, not enough support. Sometimes they don't listen to you. They seem to think carers know what's best for you...'

'...but we know what's best for us because it's our life.'

Service users want help to get out and live as part of the community.

People want enough help to join in activities and outings.

People want to get out more, especially at night, but get some help and feel safe.

Social care should take bullying seriously and do something about it.

In all the groups, people said that people with learning difficulties don't get enough help to get out in the day and in the evening, and that people should be given help to do what they enjoy.

One man said there should be more chances for people with learning difficulties to play sports. He also wanted support to go to museums and pubs. He said he liked old houses and antiques.

Another person said that they would like more new staff to take people out and about more, and that he would like to go to safari parks and historical places.
One person said they would like to have escorts on public buses so people can't bully them.

Someone else said that it would be good if it was made easier to tell someone if they have been bullied and if people took bullying seriously.

She also said that workers should listen more to what people with learning difficulties want to do and help people to do it, and not make excuses about why people can't do things.

Another person said she would like a support worker to go on public buses with her. This woman had been bullied about her race in the past. She was afraid of being attacked on the bus.

She also said she wanted help with getting a social group together. She wanted workers to listen to what people with learning difficulties want and then give the help that they are asking for.

Another person felt unsafe going out at night and wanted help at night to get out and about.

Someone else said they needed help to get out and about.

Another woman said she wanted help to go out but needed help with buses and help to meet people.

'[We need] help with finding places and I want to go to more clubs in the evening.'

'We've got to mingle, mixing in.'

People talked about how some people need support to read a menu in a restaurant.

'[I want someone to] take me out anywhere I want.'

'I would like to go to clubs and dance, do sports or swimming or tennis - you need people to help you do that. [If I had a support worker] they would show me where to go, then I could do it on my own, help me find the place.'

Someone else talked about how they would like a support worker and she said she would like them to use pictures and tapes to help her understand things.
Important things for the future

Social care should help service users do things for themselves.

Doing things for themselves does not mean doing things alone.

Helping people do things for themselves is helping the person to be themselves.

People with learning difficulties want help to live the lives they want to lead.

Service users want the choices that people without learning difficulties have.

People with learning difficulties said that the things that are important to them should be the start of any new plans for social care.

One person said social care should be about:

'Understanding what independence is.'

One woman said that in the future she wanted support to be more independent. When asked, 'what is independence for you?', she said: 'A chance to be me'.

'Being independent means looking after yourself and getting support if you need it.'

'[Social care should be about]: Being good to the service users and giving them a chance to make a life for themselves. Giving them decisions and letting them make choices about themselves. Making choices for themselves.'

Somebody else said social care should be about helping people to get over what is getting in the way of living independently.

She said social care should be about getting the support to live an ordinary everyday life, and that people with learning difficulties should have the same rights as everyone else.

She said that people with learning difficulties have been given the right by the White Paper, Valuing People, but it's not happening:
'We have to alter the minds of people in charge by becoming trainers.'

'We have the same human rights and equal rights. Leave us alone and treat us who we are, our identity, they should respect us and treat us the same as everyone else....treat us with equal respect.'

'We are allowed to make mistakes, want a job, want relationships, want what you got, but [we need] the support to get there, want a normal life but the support to get there.'

'Respect us, treat us like equals.'

One woman said this about what she wants in the future from social care services:

'Before you [social care services] make a decision, consult us first. Help us to understand what you are doing in making a change. Really consult support workers [advocates and advocacy support workers]...Involve us from the beginning.'
Word list

**Accountability:** This is when the work of a group or company shows that it is doing its work well.

**Advisory committee:** An advisory committee is a group of people that give advice about something they know about.

**Advocacy:** Advocacy is when service users speak up about what they want. They can do this with help from others using an advocacy group or speaking up group, or a person called an advocate.

**Agency:** In this paper, an organisation that gives services that is not part of a council or social services.

**Approved social worker:** A professional working in mental health who has enough skills and learning to work with and help someone with a mental health problem.

**Assertive outreach:** This is a team of people working to help people who do not use services but need help.

**Assessment:** When someone is told they need help from social services or asks to get help from social services an assessment is done. The assessment is when someone from a local authority asks the person for information about themselves and their life to work out what kind of help and how much help they need.

**Background:** In this paper, background is the country someone came from, or where their parent's came from.

**Benefits:** This is the money someone is given to help them live when they can't work because they are sick, poor or disabled.

**Black and minority ethnic groups:** People who are not white in skin colour or who come from a different culture or country than most of the people they live around.

**BSL:** British Sign Language is a way of talking with hands for people who can't hear very well.

**Bureaucracy:** is when an organisation works by a lot of rules rather than using common sense.
Care in the community: Community is the people, organisations and groups around where a person lives. Care in the community is when the people and groups around a service user help to make them better. An example could be using a local swimming pool to get better after an accident, instead of using a special pool in a hospital.

Care leaver: A person who used to get services and help from the council but does not anymore.

Care manager: The professional person working for a local authority who does a service user's assessment and writes their care plan.

Carer: Carers are people who help service users. They do not get paid. For example, a mother of a disabled child is a carer.

Community: Community is the people, organisations and groups around where a person lives.

Competence: This word means showing you can do something ok.

Complex needs: Someone who has a lot of difficult and different needs and needs a lot of different help.

Confidentiality: This means keeping information private or secret.

Consultant: A consultant is someone who does special work to make something better.

Consultation: In this paper, consultation is asking people what they think about something.

Continuity: This is when everything happens the same or without changes.

Day activities - day care - day services: These are activities in the day time, usually in a community building that give adults different things to do during the day. They are usually only for one kind of service users, such as all older people or all people with learning disabilities. They are usually open in the week and during working hours. They can also have health, social and support services.

Direct payments: This is when the money that a service user can have to help them live well is put into their bank account so they can choose what services to buy themselves.
**DOH:** The Department of Health. They are the government group that decides how people should get health services.

**Duty:** Duty is the first people a service user has contact with when they need help.

**Equality:** This means treating everyone the same.

**Facilitator:** A person in a group consultation who makes sure everyone gets a chance to talk and that the group sticks to talking about the right things.

**Flexible:** In this paper, a service is flexible if it can change how it works to help people better.

**Floating support worker:** A support worker who gives help in the home wherever a person may live.

**Fund:** In this paper, a fund is some money put aside for special work.

**Gay:** In this paper, a man who is attracted to men or a woman who is attracted to women.

**Government:** The group that rules over a country by deciding its laws.

**Holistic:** Holistic means looking at all the things that make a person, and not just looking at parts of a person.

**Independent living:** This is when a person can live "on their own" without a carer or support worker living with them all the time. They may live with friends and not completely alone.

**Key worker:** A key worker is someone who lives near service users and gives them help to live.

**Local authority:** The government organisation that runs services in an area. People sometimes also use "council" and "social services".

**Medical:** In this report, medical means a way of working that looks at problems as diseases that can be made better.

**Mild or Moderate learning disability:** In this paper, someone with a learning disability who only needs a little bit of help.
Monitoring: This means checking a service or company to find out if it does its work well.

NHS: This is the National Health Service. It looks after health services for the whole country.

Organisation: group of people who work together towards doing the same thing.

Patronised: To talk to someone as if they are a child or not as smart.

Person centred planning: This is a plan that makes what a service user wants the most important thing. What the service user wants should be what the people working to help them thinks about.

Policy: In this report, a policy is a government or professional idea on how to do something the best way.

Race: In this paper, this means the country a person was born in, comes from or background they have.

Racism: this is treating someone badly or worse than others because of where they come from.

Refugees: A refugee is someone who comes to different country to be more safe than in their own country.

Research - researcher: Research is when facts and information are looked at and questions are asked to work out how to understand something better. A researcher is someone who does this work.

Residential care home: This is a care home that only gives a service user somewhere to stay and personal care, like helping someone wash.

Respect: Treating someone as a good person.

Responsibility: In this paper, responsibility means doing something important that has to be done.

Rights: In this report, a right is something that all people should have or how all people should be treated. An example is the right for a person to be able to do things in privacy as long as it doesn't harm other people.
**Self funders:** Self funders are service users that pay for the services they get with their own money and not money from the government.

**Service provider - service provision:** A service provider is an organisation that gives services to service users. This could be getting meals delivered to a home, or having care all day and night.

**Service user:** These are people who receive the different care services. They may be children, young people, older people, disabled people or other groups. Not everyone likes the word service user.

**Service user groups:** this is a group for service users, usually run by service users.

**Services:** Services are things an organisation gives to a services user. For example, a council might send a nurse to help give medicine.

**Severe learning difficulty:** In this report, this is someone with a learning disability that needs a lot of help to live or do things.

**Shaping our Lives:** This is an organisation working to help service user groups in the community get better services for service users.

**Social care:** This is using paid people to help people, keep people safe or help people look after themselves. Social care can happen in lots of different places and can be given by lots of different people.

**Social model:** A social model is a way of looking at something. The social model of disability says that people with disabilities are disabled by things in society. This may be how people think, how to get into a building, how to read information.

**Social services:** These are services that are paid for by the government to help people have a good health and a good place to live.

**Social work:** Social work is people working to help people be well. It tries to get people to use their own things and the community to be well.

**Social worker:** A person who works for the council to help someone get better by seeing what help they need.

**Special needs:** Someone that needs a lot of help because of their disabilities.
**Standard:** In this paper, a standard is how good or bad something is.

**Support worker:** A person who works to help someone get better by giving them the help they need.

**White Paper:** This is a paper written by the Government that says the way policy and services will happen.