

## Informing the NHS England ‘making health and social care information accessible’ project

## A report on five national focus groups held with people with learning disabilities between November - December 2013



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An easy read summary of this report is available.

**Introduction**

NHS England’s main aim is to improve people’s health. NHS England wants to make sure that people can understand the information they are given about their health and care. They also want everyone to be able to get involved in decisions that affect them. Work is underway to write a new guidebook for NHS and adult social care organisations across England, such as doctors, hospitals or councils. The guidebook will be an ‘Information Standard’, which is a set of rules which organisations must follow.

The ‘Accessible Information Standard’ will tell organisations how they should make sure that patients, service users and carers can understand the information they are given. This includes making sure that people get information in different formats if they need it, for example in large print, braille or easy read. The guidebook will also tell organisations how they should make sure that people get any support with communication that they need, for example through having a British Sign Language (BSL) interpreter or an advocate with them.

NHS England wanted to seek as many different views as possible before writing this guidebook. This series of consultation events formed part of that work.

More information is available from NHS England’s website at [www.england.nhs.uk/accessibleinfo](http://www.england.nhs.uk/accessibleinfo)

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**Background Information**

CHANGE, a leading UK based human rights organisation working to promote the rights of people with learning disabilities, were asked by NHS England to lead on seeking the views of people with learning disabilities on this ‘Accessible Information Standard.’ It was agreed that focus group activity would provide the most effective opportunities for people with learning disabilities to input their views. Focus groups facilitate people being able to speak out, without the barriers inherent within written surveys. It was proposed that CHANGE worked with four other user-led organisations across the UK, running in total a set of five focus groups (one was run directly by CHANGE). The choice of groups – based in different parts of the country – enabled a fair cross section of views to be obtained. The organisations involved were:

* Grapevine based in Coventry
* The Elfrida Society based in London
* North Somerset People First based in Weston-super-Mare
* Skills for People based in Newcastle upon Tyne.

Further information about the organisations involved is contained in **Appendix Two.**

Working with known groups was seen as a cost-effective use of resources, as these groups already have established networks of people with learning disabilities who they could readily bring together. It also ensured that those consulted were supported by others who are skilled in advocacy, self-advocacy and empowerment work so that people with learning disabilities were fully able to give their views in a safe and inclusive environment. This process meant that there could be confidence that the feedback obtained was clear, well-informed and reliable.

**Overview of Work Undertaken**

In keeping with CHANGE’s model of working, two project workers worked closely together on this project, one person with learning disabilities and one without. This way of working facilitates the maximum involvement of the person with learning disabilities. In this instance, it allowed for continuity and consistency of approach between the five focus groups.

CHANGE designed an easy read leaflet to explain the purpose of the focus groups, using the services of an accessible illustrator and quality checking by the ‘Words to Pictures’ team of people with learning disabilities. The intention was that this could be circulated in advance through partner organisations with potential focus group attendees. This would enable people to make an informed decision as to whether they wished to participate in a focus group.

The two project coordinators from CHANGE worked with the partner organisations to set up all the necessary arrangements for the smooth running of the focus groups. This included liaising with partners to ensure that necessary consent procedures were in place. They set the scene and provided accessible PowerPoint slides to aid discussion. The groups ran from 10.30am to 3.15pm and included breaks for refreshments and lunch. The project coordinator without learning disabilities recorded as accurately as possible the individual, anonymised comments of focus group attendees. These are included as **Appendix One**.

CHANGE also filmed one of the focus groups and created a short film. This film highlights the views of the group around the key questions contained within Appendix One and some of the inclusive ways of working used. It can be viewed on the CHANGE website [www.changepeople.org](http://www.changepeople.org)

**Focus Group Sessions**

All focus groups followed a very similar format to ensure that the information presented was consistent between groups. The project coordinators were conscious that some of the terminology was not easy to understand, so time was spent to ensure that those present understood the words and ideas under discussion. The sessions were interactive and participants reported that they had found them enjoyable. Exercises and games were interspersed throughout the session, and snacks and lunch were provided to keep up energy levels.

The agenda included:

* Welcome and introductory games
* Setting ground rules
* Ensuring consent
* The purpose of the focus group
* Explanation of terms – What are health and social care organisations? What do we mean by communication?
* The questionnaire – via PowerPoint presentation – in two halves, with lunch in between
* Explanation as to what was to happen to the information gathered
* Thank you and good byes

Easy read materials were prepared to accompany the sessions. These included:

* An explanatory leaflet
* Informed consent form
* Agenda
* Ground rules
* PowerPoint presentation
* Picture cards of key words
* Voting cards
* Thank you certificates

**Findings**

It is worthy of note that there were some key differences between the different groups. These differences are seen as strength, as it demonstrates that a greater cross section of views was sought. Some groups had a higher proportion of participants with more complex needs than did others. Some groups had more participants who were living in some form of supported environment, whilst other groups had more participants who either lived with or had the close support of the family members. Some groups consisted of participants with more experience of advocacy and knowledge of professionals through training them. These factors may help explain some of the differences in overall responses between the groups.

The key findings of each individual session are included in **Appendix One** at the end of each table of responses. This section attempts to bring together some common themes from across the five sessions.

1. **Communication support needs**
2. *Communicating with the aid of a support person*

Often, participants would organise their own support to help them communicate with professionals, rather than relying on this being available for them. Usually, the person with learning disabilities would make their own judgement as to whether they needed support on a particular occasion or not, depending on the purpose of the contact. How successful this was varied hugely. For some participants, this worked well, as they could rely on a person who they knew and trusted to support them in understanding the professional. However, there were also many occasions when this was a frustrating, and sometimes humiliating, experience for the person with learning disabilities. There were frequent accounts of professionals talking to the support person rather than directly to the person with learning disabilities. There were some very disturbing stories in which the person with learning disabilities was deprived of information or even treatment until their support person or family member was present.

1. *Time to communicate*

People with learning disabilities consistently identified time to communicate as being critical to the success of the interaction that they had with a professional. They often equated the time that a professional took in communicating with them together with the respect shown to them by that professional.

1. *Continuity of care*

Frequent changes in the professionals involved were seen as a significant bar to effective communication. This seemed to be a particular problem in relation to social care professionals, as people with learning disabilities identified that they often had changes of worker.

1. *Providing the same information over and over again*

People with learning disabilities identified that often professionals did not seem to have read their records before seeing them; this was the source of considerable frustration.

1. *Attention to simple, practical matters can aid communication*

People with learning disabilities identified a number of simple, practical suggestions which they thought would aid their communication with professionals. For example, to have photographs of doctors alongside their names, which happens in some surgeries but by no means all. Hospitals were seen as more alienating and confusing environments and accessible signage is an issue. Quality checking by people with learning disabilities offers a mechanism for identifying and addressing these issues at a local level.

1. **Information needs**

There was an overwhelming consensus from every focus group that there is a big gap in the amount of easy read information that people with learning disabilities receive. Most participants said that they never got any easy read information and expressed this in terms of anger, frustration and resignation. On the few occasions when easy read information was available, it was generally in either the form of appointment letters or in relation to information regarding taking medication. One person asked, “If one doctor can provide this, why can’t they all?” Another queried, “If tablets can have braille information with them – why not also easy read?”

1. **The value of effective communication support and information**

Participants clearly identified that if they were provided with the right support and / or easy read information then this would be of tremendous benefit to them; as one participant said, “we would have more control over our lives”.This in turn would ease some of the pressures on health and social care, as people with learning disabilities would assume more responsibility for their own self-care.

1. **Participant’s views on the question:** **“Do you find it difficult or do you need support to see, to hear, to read, to speak or to understand what is being said?”**

There was a hesitant consensus that it would be helpful for professionals to make real attempts to find out what people’s communication support and information needs were, though this was also accompanied by some cynicism that this could become a ‘tick box’ exercise. There was also a concern about who would ask this question, how and where – would their privacy be respected?

There was an overwhelming view expressed from four of the five focus groups that this particular question was too long and too confusing and that it needed to be simpler and shorter.

1. **Sharing of records**

People with learning disabilities were understandably concerned about the privacy of their information. However, they also saw the value of professionals having systems for sharing information, particularly if this resulted in their not having to provide the same information over and over again. They were very clear that professionals should only share information when they had explained directly to the person whose information it was why this was necessary and obtained their prior consent.

1. **Health passports**

There were some interesting discussions in the groups about the purpose and value of health passports, or similar, such as information in a ‘credit card’ format. Whilst some issues were identified regarding whether the person with learning disability would have this information with them when it was most needed, it was seen as being a potentially attractive option. It offers a mechanism for having readily to hand specific information regarding communication and information needs as well as information relating to specific health conditions. This was generally seen as a far preferable option to other methods, such as bracelets, which could be very stigmatising.

1. **Training for professionals**

Unsurprisingly, given that a number of participants were involved in training professionals, this came up as the subject of discussion within all the focus groups. There was a consensus amongst participants who had been involved in training, as well as those who had not, that that training of professionals by people with learning disabilities offered a real opportunity to change attitudes and thus transform services.

**A Final Thanks**

CHANGE would like to thank the following organisations for working in partnership with us on this project: 

* Grapevine
* The Elfrida Society
* Skills For People
* North Somerset People First

We could not have undertaken this piece of work without your invaluable support. For further details on these organisations and CHANGE see **Appendix Two**.

**Shaun Webster and Anne Mackay, April 2014**

**Appendix One**

**Notes from Focus Group A held at CHANGE on 21 November 2013**

Thirteen participants took part in the Focus Group, although not all were present at the same time.

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| **Question/Area** | **Comments** |
| **Question 1** Do you find it difficult to see, to hear, to speak, to read or to understand what is being said? | 7 participants said yes to this question, 3 said sometimes. |
| **Question 2** Do you get help to communicate when you use NHS or Social Care Services, e.g. a British Sign Language interpreter? | “I get help when I go to the hospital”“I get support from my family and from support workers”“My mother helps me”“I don’t get any help”“I sometimes get help from my support worker, it depends where I am going”“Hospitals are more difficult, that is when I need help” “I have a special GP who is trained in disability issues – that really helps”“When I go to the doctors with someone else, they always ask that person rather than asking me. But it is about me!”“They see the wheelchair rather than the person”“If I want to go on my own, it can be a big problem. I can feel bullied by the doctors”“It can be very scary to go to the doctors; I can freeze up. My mum will support me. But I can answer questions, it is just difficult. My mum will take over. I want to be given more time to say things”“My doctor asks me first, and then if I don’t understand, they will ask my family. That is a good way of doing things”“They should talk to me first, but they don’t”“Sometimes it is way over my head and then I ask him [the doctor] to speak to me”“Sometimes the doctor just thinks that I have a physical disability [because I use a wheelchair] and they don’t think about the fact that I also have a learning disability”“They talk in jargon”“Some doctors stop and listen to you and respect you. Some don’t. Then it is in and out [of the surgery]. It’s like a conveyor belt” |
| **Question 3** Do you get information in a way that you can understand from NHS or Social Care Services e.g. easy read, braille, or audio? | “Generally no, I don’t understand the information that I get”“I don’t understand what medication I am on and why. I need pictures, so that I can understand” [There was lots of agreement with this statement from other participants].“I don’t understand the letters that I get – doctors love to use hard words – I think it is the way that they are trained”“It’s full of jargon”“My mum had to read the letter – easy words and pictures would be a lot better for me”“I get a text reminder [of appointments] – that really helps”“I have asthma –my mother helped me understand my medication”“I have told the doctors that I need easy read information, but they have not done anything about this”“They should give us information on pale coloured paper; I have dyslexia” |
| **Question 4** When you use NHS or Social Care Services, is there information that you are missing out on? | “I think that I miss out on a lot of things”“I don’t understand my medication”“My doctor asks me if everything is okay; she asks me what tablets I am on. Sometimes I don’t know, that is why my sister comes with me”“They should read your records before they see you, but they don’t”“I miss out on things because I don’t understand the letters that they send me”“I miss out on things because sometimes they give me information and I tell them I can’t understand it. But I am rushed out anyway”“They don’t really listen to you. They are in a hurry, I think doctors should take more time”“My social worker keeps getting changed. It is so hard to build up a relationship. I feel frustrated”“One point of contact would be better – I have had 3 different social workers”“It took me 6 months to get a social worker. A lot of services have been cut for people with disabilities”“It takes time to get to know your social worker and to make sure that they have the right information about you”“Things are better for me now, because they understand my autism. I understand my autism and I was able to get the support that I need; I go to a centre together with other people with autism. I have people around that understand autism. I am doing training on how to quality check services” |
| **Question 5** What difference does it make to you when you get the right communication support? | “We would have more control over our lives”“Everything could be better; we could do more things – we could go to the doctors on our own and get around more”“Letters are the really important issue. If they were not full of jargon we would know what they said and what to do” |
| **Question 6** Any other comments about your experiences? | “I asked for a health check. I got one straight away”“Doctors and nurses have a lot of power – we have no power – we want that to change”“I find it hard to press buttons, like the ones at my doctors, so it is hard for me to get in and say that I am there”“I can’t use the computer [at the doctors]”“They need to make sure that they give the person a chance to find out more / ask questions”“They should give us feedback”“Health care professionals need more training by people with learning disabilities”“It is really important to target training at GPs” |
| **Question 7** What do you think about this question? “Do you find it difficult or do you need support to see, to hear, to read, to speak or to understand what is being said?” | “It could be a lot better”“It is too confusing”“There are too many words”“There would need to be pictures as well”“I would find it scary to be asked this when I arrive at the doctors”“I would want to be asked in a letter beforehand”“I would want to be asked face to face” [There was not a consensus amongst participants regarding this]“I would need support to understand this question” |
| **Question 8** What is the best way to find out about your communication support and information needs? | In a show of hands, where participants could vote as many times as they wanted:2 participants wanted email communication7 participants wanted face-to-face communication4 participants wanted communication by letter – but only if it was easy read2 participants wanted online communication – but if this means a questionnaire, they wanted this in easy read with pictures3 participants wanted telephone communication3 participants wanted communication by text2 participants did not mindSome participants commented that a telephone call can be hard to understand, as the conversation can be too quick. |
| **Question 9** What should services do to make sure that you get communication support and accessible information quickly? | “This is a hard question!”“Maybe family members can help? Or friends or neighbours?”“Or maybe they need more advocacy workers? You could have an advocate via Skype”“But not everyone uses Skype or computers”“How about a free telephone service with an emergency advocate? Would that work?” |
| **Question 10** Is there anything else we should think about to find out about your information and communication support needs? | “People should listen to us. They can talk too quickly”“Sometimes they just talk at us”“Health passports are useful”“You could have a little card – it could have a chip in it with all your information on it. Or link in to the doctor’s computer” |
| **Question 11** Is there anything else that we should think about to record or share your communication support or information needs? | “They must get our permission before sharing information about us”“I want to know what the doctor is writing down about me – they should read it out to me”“They should make sure that they respect what I am saying” |

**Key Themes**

* Participants relied heavily on their families, friends and support networks for support in communicating with health and social care professionals. Sometimes this worked well, sometimes not.
* A strong concern about the lack of continuity of care, particularly in relation to social care professionals.
* Strong sense that participants wanted to be given more time in order to communicate with professionals directly.
* Strong sense of frustration at the lack of easy read information.

**Notes from Focus Group B held at Grapevine, Coventry on 3 December 2013**

Twelve participants took part in the Focus Group, although not all were present for all of the session.

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| **Question/Area** | **Comments** |
| General comments at the beginning of the session | A number of focus group participants (about a third) were from the “H team”. The “H team” members explained that this is a team of approximately 11 people with learning disabilities who are involved in training health care professionals on effective care practices; they have been operational about 10 years. Members of the “H team” explained that they had clear views that the best people to provide this training are people with learning disabilities.The team have also designed a lot of easy read leaflets – there was a feeling amongst participants that, because of this, more easy read information might be available in Coventry than elsewhere in the country. Participants expressed a concern that health and care professionals use too many jargon words. There was agreement that pictures help. |
| **Question 1** Do you find it difficult to see, to hear, to speak, to read or to understand what is being said? | Of the 10 participants present at the time:7 participants said that they did find it difficult2 participants said that they did sometimes1 participant said that they did not have any difficulties |
| **Question 2** Do you get help to communicate when you use NHS or Social Care Services, e.g. a British Sign Language interpreter? | “The doctors help me by talking to me; they let me take my time”“My doctor explains to me what is going on”“My doctor listens to me”“My doctor is very thorough; he does a lot of writing; he explains my medication to me”“Our doctor is very prompt”“My doctor doesn’t explain things to me. He talks to my Dad instead”“I am supported by staff when I go to see the doctor. That is a good thing. My carer asks my permission if she can come with me. I say yes”“My doctor talks to me directly”“I find it easier when I have a support person with me, because sometimes the doctor will use hard words and the support person explains them to me”“I have a good rapport with my GPs. If they say something I don’t like I will challenge them”“When I went to hospital, I had to wait a long time for a blood test. It made me very angry”“I don’t see my doctor very often. I don’t need to”“I find it easier with my doctors – I know them”“If I start getting anxious, my support person can explain it, so I don’t have to wait so long”“When I found out that I had diabetes, I felt scared, but my doctor explained it all to me”“Sometimes I will see the doctor with a support person; sometimes I will go on my own.”“My doctor is very good. I am happy with him. He will do home visits if I need one” |
| **Question 3** Do you get information in a way that you can understand from NHS or Social Care Services e.g. easy read, braille, or audio? | 2 participants said that they occasionally get letters with pictures on (i.e. easy read); the remaining participants indicated that they never did. All the participants expressed a strong view that they wanted information in easy read. One participant said that they got easy read information together with their regular medication saying why they needed to take it and how often. One participant commented that their local pharmacist is “generally pretty good” – that they spent time to check that the person had the correct medication and knew how to take it. |
| **Question 4** When you use NHS or Social Care Services, is there information that you are missing out on? | 10 of the 12 participants said that they thought that they got all the information that they needed.2 said that they thought that there was some information that they were missing out on – but they did not know what. |
| **Question 5** What difference does it make to you when you get the right communication support? | “It makes me happy”“I can take my medication properly”“Communication means a lot to me”“If you get all the right information, you don’t need to ask questions” |
| **Question 6** Any other comments about your experiences? | “There is a big gap between the training available to doctors, nurses and health care professionals [who get some training in learning disabilities awareness] and the training available to receptionists and others – it should be available to all”. |
| **Question 7** What do you think about this question? “Do you find it difficult or do you need support to see, to hear, to read, to speak or to understand what is being said?” | “I don’t think this is easy to understand. I would want the question in plain English” [There was lots of agreement with this statement from other participants].“It would reassure me if they asked me this”“It’s too long a sentence”“What about confidentiality – it is a personal question – where are they going to ask you?”“I think they should break it down into more than one question”“What happens if you don’t want to say?”“What are they going to do with the information, once they have asked it? Is it just a tick box exercise?”“I would want to be asked one-to-one – I would feel shy and embarrassed to answer this”3 participants said that they would want the question to be asked in a form or a letter. 8 said face to face. 1 was not sure.One participant commented that they did not like the word ‘difficult’ they wanted it to say ‘hard’; participants were comfortable with the term ‘support.’ |
| **Question 8** What is the best way to find out about your communication support and information needs? | In a show of hands, where participants could vote as many times as they wanted:None of the participants wanted email communication10 participants wanted face-to-face communication6 participants wanted communication by letter – but only if it was easy read1 participant wanted online communication5 participants wanted telephone communication4 participants wanted communication by textParticipants also pointed out that not everyone uses, or has access to, a computer. |
| **Question 9** What should services do to make sure that you get communication support and accessible information quickly? | “I think that there should be more training of paramedics and ambulance services by people with learning disabilities”“My health passport has all my details on – that should help in an emergency; it makes things easier for paramedics and it means that I get seen quicker because the doctors know what my needs are”“But not everyone has one [a health passport]”“I would not agree with wearing a wrist band. I think that would be stigmatising” |
| **Question10** Is there anything else we should think about to find out about your information and communication support needs? | “My [doctor’s] receptionist has a computer where you sign in. It can be very hard to do this”“I like it when the doctor comes out and calls my name”“I think that the doctors should have their photos in reception, not just a name board”“Why can’t they have support workers who are based in the doctors’ surgeries?”If that would cost too much [to have support workers in doctors’ surgeries], there should be at least someone available who is trained in communicating with people with learning disabilities”“Home visits are good” |
| **Question 11** Is there anything else that we should think about to record or share your communication support or information needs? | Very clear consensus that health and social care professionals need to discuss it with the person concerned, and get their agreement, before sharing any information about them.“It’s about you, it’s not about them”There was a clear demand that people with learning disabilities wanted consideration and respect; part of that was seeking consent before sharing or discussing confidential things that might also be embarrassing. |

**Key Themes**

* Emphasis on wanting to be treated with respect, for example, “they should listen to us” and “treat us as equals.”
* Some positive experiences, which participants equated to professionals having had access to training from people with learning disabilities.
* “People like us should be able to train professionals on learning disability awareness.”

**Notes from Focus Group C held at Elfrida Society, London on 9 December 2013**

Eleven participants took part in the Focus Group.

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| **Question / Area** | **Comments** |
| General comments at the beginning of the session – health care | “I can never get a GP appointment when I need one, this causes me stress”“The NHS in prisons needs improving for people with learning disabilities”“Training needs to include receptionists as they are first point of contact for people with learning disabilities”Some participants shared good experiences with their GP, including getting double appointments (i.e. twice as long) to give people with learning disabilities more time to explain themselves without being rushed. However, participants agreed that this is not common practice.“I would like continuity and the same GP”“I would like to take my advocate with me; some doctors don’t seem to like this due to confidentiality”Participants would like easy read explanations of conditions to be available, for example about diabetes, thyroid problems, high blood pressure and healthy eating.“Same services need to be in place for everyone”“Doctors talk too much, they need to listen more and give people with learning disabilities more time.“I was misdiagnosed as my GP didn’t give me the time to explain what my symptoms were”“A training group has been set up in Camden where people with learning disabilities provide training, so that all new staff in the hospital are trained by people with learning disabilities in communication skills.”“Professionals need to ask themselves ‘is the information accessible’?”“Opticians need to be reminded to explain what they are going to do next, they shouldn’t put eye drops in your eyes without telling you what will happen and it will hurt” “Professionals don’t always believe you when you say you have learning disabilities. If they don’t believe you it can affect everything”Participants identified that they would like continuity of professionals and had had mixed experiences in their contact with nursing staff. “When you go to the chemist, if they have no medication available, it is frustrating that you have to come back to collect your medications, you may forget”“With dentists, one missed appointment means that you are struck off the NHS list, they should give people with learning disabilities more discretion. We may have a valid reason for not being able to go to the dentist”“I see the physiotherapist, but I don’t always get appointment letters in easy read”Participants gave lots of examples of experiences of getting lost in hospitals, and there being lots of departments. They wanted signs with pictures or colour coding, and a ‘meet and greet’ person to help them.Participants stated that they need support when getting results as they do not understand the implications. |
| General comments at the beginning of the session – social care  | “Personal assistants are brilliant but it takes so long to go through the assessments, but it was great once I got a PA [personal assistant]”“Respite care in an emergency is really good; it is good when they respond quickly”“Social workers need training around listening to people”“When you get a personal assistant it works well”“Day centres are good if they are relevant and not boring”“I find that social workers don’t get back to you, they don’t understand people with learning disabilities, and get caught up in the paper work they have to complete”“I don’t know how to make complaints [about my social worker] their workloads are too high”“They [social workers] need to be trained in how to listen to people with learning disabilities; they need training from people with learning disabilities”.“We need more organisations like Shared Lives, they give you a chance” [“Shared Lives Plus is the UK network for family-based and small-scale ways of supporting adults.” See [www.sharedlivesplus.org.uk](http://www.sharedlivesplus.org.uk)]  |
| General comments at the beginning of the session –information  | Participants agreed that all written information they receive needs to be easy read.Participants commented that people with learning disabilities need access to universal services and therefore letters need to be easy read. |
| **Question 1**Do you find it difficult to see, to hear, to speak, to read or to understand what is being said? | “People in power need to slow down and listen. They ask you if you are ok and do not listen to the answer”“They need to be patient with us”“They should not use jargon”“We want information in easy read”“Not small font size”“Training needs to be given by people with learning disabilities” |
| **Question 2**Do you get help to communicate when you use NHS or Social Care Services, e.g. a British Sign Language interpreter? | 1 participant said yes 4 participants said sometimes6 participants said no“If I got easy read letters, I wouldn’t need help”“If I had support and guidance, it would make my experience better”“It is important to have the right forms”“My support worker has helped me and that has made a difference” |
| **Question 3**Do you get information in a way that you can understand from NHS or Social Care Services e.g. easy read, braille, or audio? | 2 participants said yes2 participants said sometimes5 participants said noParticipants identified things that would help them understand, including information that is more accessible, pictures, no jargon and easy read. “If they send you a letter asking you to come for a test, I would like to know what the test will involve to prepare myself”“Health Action Plans are should be easy read but they aren’t” “I think it is a post code lottery”None of the participants had a health passport; all thought it would be a good idea.One participant shared a positive experience, “I go for a regular health check just because I have learning disabilities. This works well for me” |
| **Question 4**When you use NHS or Social Care Services, is there information that you are missing out on? | 8 participants said yes2 participants said sometimes1 did not respond“We need leaflets in easy read”“Doctors and nurses need more confidence to be able to just ask ‘have you got a learning disability?’”“There should be links into the learning disability service and information they have on you”“There should be a national database that tells professionals if you have learning disabilities”“I have had professionals say to me ‘you don’t look like you have a learning disability’”“They should look at school records, the SEN [Special Educational Needs] service needs to link into adult services”Participants agreed that there needs to be good information sharing from school to adult services. 1 participant identified issues when learning disabilities are not diagnosed until adulthood. “It is ok for professionals to ask ‘do you understand?’ or ‘is it clear?’ They should not presume”“A doctor said to me that ‘you don’t look like you have learning disabilities. I took a test. He said sorry that he didn’t believe me” |
| **Question 5**What difference does it make to you when you get the right communication support? | “I think it makes a huge difference because it’s easy for the individual to understand an easy read letter. It takes a lot of weight off our shoulders”“Make sure communication is clear and easy to understand”“Have patience and make sure they don’t talk jargon”‘When they write letters, put it in large print and add a few pictures and highlight the important things like the date and the time” |
| **Question 6** Any other comments about your experiences? | No responses.  |
| **Question 7**What do you think about this question? “Do you find it difficult or do you need support to see, to hear, to read, to speak or to understand what is being said?” | Participants strongly felt that this question is too long.“You could ask ‘Do you have a learning disability?’”“Should use a, b, c or 1, 2, 3” [to break the question up and make it easier to understand].“It is confusing”“They should separate things out”“Slow the sentence down”“Use smaller words”“Will the statement be accessible?” [i.e. in easy read]“Who is going to ask?” |
| **Question 8**What is the best way to find out about your communication support and information needs? | In a show of hands, where participants could vote as many times as they wanted:3 participants wanted email communication6 participants wanted face-to-faceNo-one wanted a letter if was not accessibleEveryone wanted a letter if it was accessibleNo-one wanted online communication8 participants wanted telephone communication5 participants wanted text communication1 participant did not mind what method of communication |
| **Question 9**What should services do to make sure that you get communication support and accessible information quickly? | “There needs to be a national database, but we want to agree that our information can be shared”“Hospitals and GPs should know you and so should the primary care professionals working with you”“A bracelet identifying that you have learning disabilities could make people vulnerable”“I like the ones [bracelets] where there is a small barrel and issues are covered up”“Health passports are good – they need to be used more”“GPs should take more responsibility for passing information on”“There is a balance between sharing information and labelling us”“ALL should be trained in making information accessible; this small thing would make a huge change”“The GP’s, hospital staff and receptionists should all work together so that they have the same information. That does not happen at the moment”“They should speak to you regularly, check in with you and make sure you understand”“They should send easy read information using pictures, easy words and in big print before your appointment so you have time to look at it beforehand. Then you will be ready for your appointment”“There should be easy read leaflets readily available about our conditions. That should be across all health services” “Leaflets could be on the GP computer, so to not waste paper. But the GP needs to know about them so they can print them out when they see you”“They need to go through the information with you and take time. They should give you double appointments”“There needs to be more training to get staff to understand about not using jargon and being clear” |
| **Question 10**Is there anything else we should think about to find out about your information and communication support needs? | No responses.  |
| **Question 11**Is there anything else that we should think about to record or share your communication support or information needs? | “If they talked to each other, that would be a positive”“Information is sometimes sent straight from hospital to GP; I would like a copy”Participants agreed that it has caused confusion when they had moved from one borough to another, due to information not being shared. |
| Final Thoughts | “They need to ask us [people with learning disabilities] what is ‘easy read’; often professionals try and make it easy read and think they have done a good job, but they haven’t”“There should be a picture for every sentence”“Easy read is everything”“We want to check the interpretation of images”“Test out with people with learning disabilities if images ‘work’”“I would like to be there to be more focus groups before the guide is published to test the draft of the guide”“People with learning disabilities are the experts”“I don’t want the NHS to be tokenistic; we have come this far; do the job properly” |

**Key Themes**

* Easy read information, the availability of good advocacy services and professionals with good listening and communication skills are very important.
* Participants highlighted the importance of professionals being trained by people with learning disabilities.
* Health passports (or equivalent) would be good if they were properly rolled out across the country.
* Professionals do not always believe people when they say that they have a learning disability.
* Participants made some very negative comments about social workers. However, they also had some good experiences of social care provision - but stated that it takes too long to get this support.

**Notes from Focus Group D held at North Somerset People First, Weston-super-Mare on 10 December 2013**

Nine participants took part in the Focus Group.

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| **Question/Area** | **Comments** |
| General comments at the beginning of the session | “It is important to get the right health care.” Participants generally felt that it is important to get the right treatment and understand the treatment that they are getting. They felt that being given the correct advice was a crucial part of this.A number of participants explained that they were unable to use the 111 telephone number; they did not understand it and needed support to access this service. Participants wanted more out-of-hours face-to-face services.Participants appreciated getting the right support and help from their individual Personal Assistants.Participants reported having experienced being shouted at by dentists.Participants identified having had frequent changes of social worker and that they did not like this.Participants shared experiences of professionals taking a long time to give feedback and to pass information on.Participants felt that buddying schemes worked well. The buddy scheme helps children and young people with complex additional needs to access social and leisure activities in the community, for example youth clubs, shopping trips and after-school clubs. “The consultant talked to my parents rather than me. The consultant then said to my parent ‘she doesn’t understand, does she, as she’s got disabilities’. I said ‘yes I do’.”Participants would like to be prioritised when going for appointments, as long waiting times cause them stress. |
| General comments at the beginning of the session – health care  | “10 minutes is not long enough – I need double appointments as I don’t get time to explain things”“I don’t like changes of doctors. I need the same one to give me consistency” Some participants recounted experiences of not being listened to and of professionals being rude to them.“Sometimes the chemist has run out of medication and I have to go back for it. It causes stress and is frustrating”Participants found the different uniforms worn by staff in hospitals confusing.Participants shared both good and bad experiences of nurses, including instances where they felt listened to and cared for. “The doctor always talks to support workers and my parents - not to me. I don’t like this”“I need doctors and professionals to explain what they are doing”“Doctors don’t know any Makaton; they should have some specialists who have extra training”“I was told I was making things up. My support worker challenged this – how can I make up my disability?”“I find it confusing to find my way around the hospital. It is good when hospitals use coloured signs and colours on the floor”“Meet and greet people need more patience and extra training in how to deal with people with learning disabilities”“Small hospitals are changing which means hospitals are bigger and have more departments. It is therefore harder for me to get around”“Receptionists and other staff who are the first point of contact need extra training and patience in how to deal with people with learning disabilities”“Accessibility needs looking at, we need to get the practical things right as well”“You should think about having specialists in learning disabilities in each hospital and GP practice” |
| General comments at the beginning of the session – social care | Some participants had positive experiences of care homes, but this was not universal. Some participants identified problems in having limited choices, for example no private televisions and not being allowed visitors when they wanted.Some participants had experiences of living in shared houses, and having limited privacy in their own home.One participant explained that he spent time living in a group home with people with mental health issues, which he found frightening. Participants recounted some positive experiences of respite care. One participant commented that they felt that respite worked well if it was provided in another’s person’s home, rather than in a care home.Some participants identified that they needed help to learn independence skills, for example “support workers need to push me and help me learn new skills” and “I would like more training opportunities for me”One participant reported an experience of emergency accommodation that had been stressful.Participants strongly agreed that they did not like continuous changes in social workers and occupational therapists.Some participants explained that they found day centres boring, for example because people had more severe or profound learning disabilities than they did and / or they felt that they did not fit in. Some participants commented that they liked new day centres that had been updated, for example with sports facilities and those that are activity-based. They felt that day centres are okay, if they are not ‘old-fashioned.’One participant said that they will miss seeing their friends at the youth centre as it is closing down. “There is nothing for young people with learning disabilities to do. We need to meet people our own age”Participants stated that they would like more experiences like Shared Lives. [“Shared Lives Plus is the UK network for family-based and small-scale ways of supporting adults.” See [www.sharedlivesplus.org.uk](http://www.sharedlivesplus.org.uk)] |
| **Question 1**Do you find it difficult to see, to hear, to speak, to read or to understand what is being said? | Participants wanted to consider each part of this question separately.4 participants identified difficulties in hearing5 participants did not identify difficulties in hearing9 participants (i.e. all) identified problems in speaking4 participants said that they sometimes had difficulties in reading5 participants said that they did not have difficulties in reading“I wish that there were more peer-to-peer communication support – that would help”“Professionals explain things. But sometimes I find it too hard to understand”“Professionals explain things too fast”“I like it when we get the chance to ask questions”“I like it when people listen to us”“I find it ok to speak”“I find it ok to read if my support worker helps me or it is easy read” “I find letters from the GP hard to read sometimes. It would be better if there were in easy read and picture-based”“Often letters from professionals have long words”“If I didn’t have a support worker, no-one would make sure I could understand the letters I get” |
| **Question 2**Do you get help to communicate when you use NHS or Social Care Services, e.g. a British Sign Language interpreter? | “I get support to go to the GP from my family and friends”“I have never had any easy read letters or documents from any health or social care organisations”“It would be better if I had a face-to-face discussion or easy read information or if someone used Makaton”I need more time to communicate properly – I want a double appointment”“The receptionist had to ask the GP’s permission to let me have a double appointment. Why didn’t they just trust me?”“I don’t feel listened to by the receptionist. I feel I am sometimes ‘fobbed off’” |
| **Question 3**Do you get information in a way that you can understand from NHS or Social Care Services e.g. easy read, braille, or audio? | 4 participants said yes3 participants said sometimes2 participants said noParticipants commented that they often used residential care or support staff to interpret letters for them, “I don’t know what I would do if I didn’t have them.”Participants identified that they needed letters in bigger font, with pictures, easy read and bright colours.Participants stated that leaflets were often put in the bin.Participants identified texting to remind them of appointments as being a really good idea. Participants also suggested an email follow up, but not to rely on this.“A letter would be ok, if we could understand them on our own”“We don’t want loads of paper. It is hard to tell what is important”“I get used to one system, then it changes”“I sometimes forget appointments, so it is good to get reminders”“If we are a few minutes late for appointments, it is often not our fault. We need extra leniency” |
| **Question 4**When you use NHS or Social Care Services, is there information that you are missing out on? | “Not telling you enough in appointments, it can take ages to pick things up” |
| **Question 5** What difference does it make to you when you get the right communication support? | A flip chart exercise was used for this question, and participants identified that a perfect service would be one where:* Medication is explained
* Staff talked to them and listened
* There was understanding of their individual support needs
* More support workers were available

“111 service needs to be more accessible for people with learning disabilities.” “It should be common sense. For example, professionals should speak to the individual person not the support worker. But the person with learning disabilities gets frustrated and upset that they can’t get the point across and don’t understand the questions being asked”“Training needs to be given by people with learning disabilities”“Waiting times need to be cut down for people with learning disabilities”“Receptionists need proper training around communication”“We need more disabled parking”“We need 24 hour services”Participants then considered the impact on them when they do not get the communication support they needed. They said that this made them feel: grumpy; unhappy; stressed; tired; angry; anxious; moody; emotional; in pain (as they were not getting the service). |
| **Question 6**Any other comments about your experiences? | No responses.  |
| **Question 7**What do you think about this question? “Do you find it difficult or do you need support to see, to hear, to read, to speak or to understand what is being said?” | Participants generally liked this question. |
| **Question 8**What is the best way to find out about your communication support and information needs? | In a show of hands, where participants could vote as many times as they wanted:3 participants wanted email communication8 participants wanted face-to-face communication2 participants wanted online forms2 participants wanted telephone communication6 participants wanted text communication4 participants wanted a letter - if it was easy read1 participant did not mind |
| **Question 9**What should services do to make sure that you get communication support and accessible information quickly? | “My community alarm service works really well, it makes me feel safe; but why do we have to pay for it?”Participants liked the concept of an emergency card with all their details on it that they carried with them.Some participants stated that they would feel okay wearing a bracelet or necklace which contained important information about them, but it needed to be fashionable.“It would be good if some ambulance drivers had extra training in learning disabilities and Makaton”Some participants reported good experiences of first response cars, for example “it helped to calm me down until the ambulance came” |
| **Question 10**Is there anything else we should think about to find out about your information and communication support needs? | No responses. |
| **Question 11**Is there anything else that we should think about to record or share your communication support or information needs? | 6 participants said yes3 participants said no“I feel okay generally about having information shared about me, but I would like to be asked about ‘my story’ as well” |

**Key Themes**

* Easy read information is important.
* Training by people with learning disabilities is important.
* The first point of contact with a service – often a receptionist – has a crucial role in ensuring that contact begins with positive start.
* Participants think a ‘learning disabilities’ bracelet could help, and were positive about wearing one, if it was fashionable.
* Many of the participants had a health passport, and had found it useful.

**Notes from Focus Group E held at Skills for People in Newcastle on 16 December 2013**

Eight participants took part in the Focus Group.

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| **Question/Area** | **Comments** |
| General comments at the beginning of the session – health care | One female participant commented that it was very important to her to be seen by a female doctor.Participants felt that being involved in the training of health professionals was very important and was making a big difference to how things were being done. Some participants were involved in training through Skills for People. Participants wanted to acknowledge the excellent services provided by ambulance crews.One participant commented that their pharmacist was really helpful as they provided home delivery of prescriptions. However another participant noted that braille was available on the tablet pack, which was seen as being very helpful, but they wanted the same information to be routinely available in easy read as well. |
| General comments at the beginning of the session – social care  | Participants commented that social care was very important – that they needed carers to help them with everyday tasks such as cooking.“I don’t trust my social worker – they try and tell you what is best for you”“I tell them what I want, but they don’t hear”“Sometimes they listen, sometimes they don’t”“I never see the same person twice” |
| General comments at the beginning of the session – communication | “I can really tell the staff that have had training by a person with learning disabilities – it should be a requirement for all medical staff to have specialist training by a person with a learning disabilities”“I think we should get them when they are first in training – they are more likely to listen!” |
| **Question 1** Do you find it difficult to see, to hear, to speak, to read or to understand what is being said? | Very mixed reaction and responses from participants to this question. A number of participants said that they found it difficult to read information.“I have dyslexia, so could not read information”“It would depend on the situation and what was being asked”“I would ask for support” |
| **Question 2**Do you get help to communicate when you use NHS or Social Care Services, e.g. a British Sign Language interpreter? | “I always take someone with me [when I use services], as otherwise I would not understand. I organise it myself in advance” “I prefer it when I can talk directly to someone on a one-to-one basis”“I do not need any communication support, I feel confident to speak up because I have been part of the group that trains health professionals”“I do not like to take someone with me when I go to see a doctor, because if I do the doctor only talks to my support person rather than direct to me”“I take a carer with me, but the doctor still talks to me rather than to my carer. If I do not understand what the doctor says, I ask my carer to explain”“I often do not understand, but I keep on asking questions until I can understand. I do not give up”“I want a lot more time at the doctors” [There was lots of agreement with this statement from other participants].One participant said that their GP gave them as much time as they needed. Another added that they thought it was the job of their doctor or social worker to provide the support that they needed.One participant emphasised that they could not manage without things being explained clearly to them. They needed things to be explained in ways that made it easy to understand.One participant said that they felt very nervous when they visited their GP. They wanted their GP to be more patient with them and to give them more time to understand. They said that they felt less nervous when they visited their GP accompanied by a carer. |
| **Question 3**Do you get information in a way that you can understand from NHS or Social Care Services e.g. easy read, braille or audio? | None of participants had received any easy read information from their GP or from specialist health services. One participant said that they did get easy read information from the pharmacist. Some of the participants had not thought about the possibility of audio information being available – and they thought that this would be a good idea.All participants, without exception, wanted to be provided with easy read information.One participant particularly identified easy read information in relation to their medication as a priority. They wanted easy read information to explain how and when to take their medication. They wanted pictures on their medication box. [There was lots of agreement with this statement from other participants].  |
| **Question 4** When you use NHS or Social Care Services, is there information that you are missing out on? | “I have put letters from my GP in the bin, because I could not understand what they said”“I could not read it, so I don’t know what the letter said”“It is very frustrating not to be able to understand things”“I have a support worker who reminds me if I have a hospital appointment and puts it in the diary”“I have missed hospital appointments because I have not understood the letter”“I have done training with student doctors and this helped them understand what the issues are for people with learning disabilities” “I gave up and went away”“I missed an appointment. I was not very happy. I think it is really bad the way that they treat people with learning disabilities” |
| **Question 5**What difference does it make to you when you get the right communication support? | “It really helps to get the right information”“I need less things explaining to me [when I get to the appointment] so I know what is going to happen”“I don’t need to go to the doctors as much”“I have had such bad experiences, I can’t imagine what it would be like to get the right support”“It makes a big difference – if it was easy read, I could understand it better myself”“If I got the right information, I would feel so confident”“I try and see the same doctor if I can. That makes a big difference to me”“I would love it if I could see the same doctor all the time. But I can’t”One female participant said that getting the right support meant getting to see a female doctor.One male participant commented that he wanted to see a male doctor. |
| **Question 6** Any other comments about your experiences? | “I don’t always want a carer to know about my business. So I avoid going to the doctor’s if I can.”“If you ask the right person, [the person with learning disabilities themselves] you get the right information”“Doctors are always in a hurry. I think they can be very rude”“Some doctors have a prescription written out before you get in the room. They don’t seem to have time to listen”“I often can’t get a doctor’s appointment when I want one”“I can have a 10 minute appointment with my doctor straight away or I can wait for a double appointment”“It is like being on a conveyer belt”“My doctor gives me a long appointment because he has been trained by a person with learning disabilities”“My doctor always offers me a longer appointment”“Mine does not. I want more time so that I can speak properly to the doctor; I can’t do this quickly”“I went in to my GP for a health assessment. I felt very stupid because no one explained it to me properly”“They don’t always look in the records to see what support or information we need”“I needed an injection. I gave my consent. But they would not believe me. I felt patronised. They did not listen to me and asked my carer instead. But I have mental capacity. Why would they not accept that? It really knocked my confidence”“My mum lost [mental] capacity; she was in hospital and I was visiting her. My mum was talking, but not making any sense. I went to talk to the nursing staff. They would not tell me what was wrong or what was happening. I had to wait until my Dad came before I could find anything out. It was terrible”“They see the label, the disability. The think that you don’t understand things, when you do. It is not fair”“I have had a bad experience in hospital. They put me in a side room the furthest away from the nurses and everybody else. They seemed to expect my support staff to do all the things that the nursing staff would do with anybody else”“I can’t get an appointment when I want one at my doctors” |
| **Question 7** What do you think about this question? “Do you find it difficult or do you need support to see, to hear, to read, to speak or to understand what is being said?” | “It’s too complicated; if I was asked all that, they would lose me!”“Why don’t they just ask ‘do you need any support?’?” [There was lots of agreement with this statement from other participants]. There were some concerns about being asked this question by a receptionist, as it might not be private. |
| **Question 8** What is the best way to find out about your communication support and information needs? | In a show of hands, where people could vote as many times as they wanted:3 participants wanted email communication7 participants wanted face-to-face communication6 participants wanted communication by letter – but only if it was easy read1 participant wanted online communication5 participants wanted telephone communication3 participants wanted communication by text“Is this information not in a health passport?” This prompted some discussion about the fact that not everyone had a health passport, resulting in a lack of clarity about what they were and what information should be or could be included.One participant said that they had a health passport just for going to the dentist.One participant said that a health passport was only any good if it would fit in their pocket. Another participant said that they were worried that they would lose it or not have it with them when they needed it.One participant said that they had a health action plan and their needs in relation to communication support and information were included as part of that.One participant shared a bad experience of being admitted to hospital. They had not received medical attention until their carer arrived. The carer was then used as a communicator. “I am exhausted asking for accessible information. I have given up asking for it”“The system is supposed to flag up that I have learning disabilities but it does not work, or they don’t bother checking, because they don’t seem to know”“They should not make assumptions and put us all in the same box. They should ask” |
| **Question 9** What should services do to make sure that you get communication support and accessible information quickly? | One participant made a suggestion that they could carry a little card in their wallet which contained information about their communication and support needs. One participant suggested that all the information should be kept on a computer database used by the doctor and hospital, so that they did not have to be asked every time that they went. |
| **Question 10** Is there anything else we should think about to find out about your information and communication support needs? | “Check my records. The information is there”“I want the same person so that I don’t have to tell the same information over and over again”“I want to be listened to”“I want them to do what they are supposed to do” |
| **Question 11**Is there anything else we should think about to record or share your communication support or information needs? | No responses.  |

**Key Themes**

* Participants felt that people with learning disabilities training health and social care professionals makes a real difference to how people with learning disabilities are perceived and treated.
* Participants had low expectations in terms of easy read information – they wanted to have this, but almost never got it.
* Participants had very mixed experiences of health and social care professionals, some good and some not so good – one important factor in how participants perceived these experiences was whether they were treated with respect and communicated with directly.
* Participants wanted to make their own decisions in relation to their health care; being provided with good communication support and information was seen as an essential part of this.
* Some participants felt very frustrated when the information was already on their records and yet they were asked over and over again.

**Appendix Two – Organisations involved with the Focus Groups**

**CHANGE – based in Leeds**

CHANGE is a leading UK based human rights organisation led by Disabled People. CHANGE empowers people with learning disabilities by actively campaigning for equal rights and inclusion. CHANGE undertakes project work on issues that are important to people with learning disabilities such as enabling the transition from childhood to adulthood, promotion of health equality, access to housing and combating hate crime. CHANGE is a fully engaged partner within the Department of Health, NHS England and Public Heath England Strategic Partnership Programme with the Health and Care Voluntary Sector. CHANGE delivers training and produces a wide range of accessible information. People with Learning Disabilities are involved in developing every aspect of the work. CHANGE promotes innovative employment models and has experience of employing people with learning disabilities on a proper salary for over 15 years. [www.changepeople.org](file:///%5C%5Ccp-server%5CRedirectedFolders%5Canne%5CDocuments%5Cwww.changepeople.org%20)

**Grapevine – based in Coventry**

Grapevine helps people with learning disabilities to get the life they want – to make their own choices and be part of the community. Grapevine wants to reduce the isolation that so many people with learning disabilities experience. Grapevine helps people with learning disabilities make connections and have a life in the ordinary world. Grapevine run a number of different projects, including the “H Team”, who train around 200 health professionals each year. The “H team” were winners of a 2014 NHS England Excellence in Participation Award. [www.grapevinecovandwarks.org/](http://www.grapevinecovandwarks.org/)

**The Elfrida Society – based in London**

The Elfrida Society is a leading charity based in Islington, London for adults with learning disabilities. The Society’s aim is to make it possible for people with learning disabilities to manage as much of their lives as they want and feel able to. The Elfrida Society has several projects relating to the arts, health, advocacy, sport and parenting support. The access to health project supports adults with learning difficulties to access health services and provides essential support to understand complex conditions or procedures. The project also encourages local health services to become more accessible, through providing health advocacy, information, promotion and training. [www.elfrida.com/](http://www.elfrida.com/)

**North Somerset People First – based in Weston-super-Mare**

North Somerset People First is a self-advocacy organisation for people with learning disabilities. They support people to speak up for themselves so that they can achieve their life goals. They are managed by an elected committee, who all have learning disabilities. Amongst other things, they support people with learning disabilities to speak up for themselves and be aware of their rights, take part in consultations by talking to people about the services they receive and what they want from those services. They also provide training. [www.listentoourviews.org/](http://www.listentoourviews.org/)

**Skills for People – based in Newcastle upon Tyne**

Skills for People are a user-led, voluntary organisation working in the North East. They work to make sure disabled people can be in control of their own lives, strong, confident and included in the communities of their choice. Their dream is a world where all people are valued and treated fairly, people are not left out because they are different and disabled people are strong, confident and living the lives they choose. They offer training, consultancy and support for organisations which support disabled people. [www.skillsforpeople.org.uk](http://www.skillsforpeople.org.uk)