

Page reference: Patient perspectives / Landing page

Video 1: Six lives

Narrator	This film is a snapshot, it's a moment in time over a few days where real people have talked to our champions to express some of the issues that face them when accessing healthcare.
<i>Supporter</i>	<i>Have you ever been to a hospital, have you ever been to a GP, how did you find it?</i>
<i>Service user</i>	<i>Yes, yes</i>
<i>Supporter</i>	<i>Did they treat you OK?</i>
<i>Service user</i>	<i>Mm hmm</i>
<i>Supporter</i>	<i>Did they explain to you?</i>
<i>Service user</i>	<i>Yeah</i>
<i>Supporter</i>	<i>And you have been to the dentist, and were they treating you good?</i>
<i>Service user</i>	<i>Yes, thank you.</i>

Narrator

I hope this film will help us talk about some real issues. In doing this we found lots and lots of positive things about individuals within the system and areas where things worked very well. We also found some examples which were not so good and we also found some examples which were not acceptable.

This film is about establishing a way in which we can talk together about these things so that together we can move forward to make change. I, like you, want a health service which responds to us as individuals and meets our individual requirements in a way in which we feel comfortable with and this is about all of us, not about a special or segregated group of people because the views that are expressed in this film are things that affect everybody, not just people with learning difficulties.

Supporter *If the doctor phones you...*

Service user *It's my mum not me. I can't stand the doctor.*

Supporter *You don't stand doctor?*

Carer#1

I think the doctors, professionals, they need to be educated. They have very little understanding of how to deal with people with mental illnesses. I think they are very good at dealing with physical disabilities but not mental disabilities.

Supporter *Is that good or bad? Or all right...[inaudible] bad.*

Carer#2

I've not had very good experience with doctors so far. I find that they are very impatient, and they say the government's putting pressure on them and they only have a certain allocated time. If you could vet for more time, fair enough. Other than that, then they just squiggle down a prescription and they just shove you off.

Supporter

You know your teeth? Yes, you had some fillings done. How did you feel about it, was that good, all right, or bad? Good. So you were happy with that treatment, good.

Carer#2

Most of the dentists I have been to with some of my friends who are service users. Same thing, the dentists are very impatient. They just want to do the treatment as fast as possible. Sometimes they're not very sympathetic to the understanding of the patient and they'll use long words. They won't explain what they are going to do, they just sort of prop the mouth open and you get a bad reaction. You know, they're scared, they don't know what's going on. Strange feeling, strange atmosphere, strange smells. I find that a little bit of patience, a little bit of time explaining to someone what you're going to do, helps a lot

Supporter

When you go to the dentist, maybe you might need some medicine afterwards to help with pain in your mouth. Do you feel that it's good, OK or bad? You've put it in the bad. OK.

Carer#3

One of the service users, she had very bad toothache due to her teeth were rotting. And when we took her to the dentist, the dentist don't want to see her because, you know, and they said oh, you need to, we'll refer you to London Hospital but he didn't wish to even check to see what's wrong. And she was in pain.

Supporter

When you went to see your dentist, there were other nurses. How did you feel about them, were they good, were they alright, or were they bad?

Uh-oh. You don't like them very much. So you are saying that the staff was bad, yes?

Service user *Yeah.*

Supporter *OK*

Carer#4 Well, with the clients, I've experienced with the doctors kind of deal with them at arms length.

Supporter *Because remember you said a doctor didn't treat you fair, So where would you like to put this one? I'll give it to you, and where do you want to put it, in good, all right or bad?*

Service user *Bad.*

Supporter *So this is bad, this area is bad. This one is all right and this one...*

Carer#5 I must say, a doctor I had, I don't know what perception she had of my son but when she had to come to the house, she was so scared of him that she actually diagnosed him from standing from the other side of the room. And we're still not sure if that diagnosis was right but she was too scared to come up close in case she got bitten.

Carer#3 It's all about trust as far as I know and if the doctors handle the patient roughly, especially with people with learning difficulties, and have no sympathy whatsoever, then obviously, you know, it's going to cause a problem.

Supporter *How did you feel about the examination, the dentist looked at your teeth? How did you feel about it? Did you think it was good, was alright, or bad? You can put the symbol next to good, alright or bad. What do you think? Where would you like to put it, the examination? You can just stick it on the map somewhere. Good, alright or bad.*

*Where do you think it went? Is it good, alright, or bad?
Which one? Good.*

Carer#3 I think they should communicate more with the patients, especially with the people with the speech impairment, use sign language because that's how they can communicate, so the patient's comfortable and the doctor knows what he is doing because if there's no communication there is no point, basically.

Supporter Wonder what you think of the doctor.

Supporter Do you like the doctor...

Carer#5 Because there is people with physical disability or learning difficulties who can speak for themselves, but then you've got those who can't speak for themselves so that it's got to be established right from the beginning who is the person, they've got to identify the person who they've got to speak to

Supporter So what you've told me so far is that the dentist was good, yes, the communication was good, the medication was good, yes, the treatment was good, the information was good, waiting time was alright, yes, the examination, the whole examination was alright and the staff, the other staff were bad.

Carer#2 Somebody with a learning disability, especially if somebody is doing Makaton all the time, can't express themselves as fast, may need interpreter and I find, doctors are not as patient. They are continually looking at their watch for time. And they're getting frustrated. I think it's the lack of understanding, a lot of ignorance and a lack of patience as well. Instead of giving them that

little respect, the little eye contact, the little smile, the little 'OK, can you tell me where it hurts, can you show me yourself?' Instead of looking at someone else and saying 'Er, where did you say he hurts, where did...?'. They are a human being, talk to them. Not all of them are deaf and even the ones who are deaf can lip read. So give them that little respect, be a little bit more patient with them, and talk to them like human beings.

Supporter

Did they communicate with you good? Is a good communicate, did they talk to you nicely, or badly, or all right?

Carer#4

There is this preconception, you can't talk so I can't communicate with you, which is ...nothing could be further from the truth.

Supporter

Are you looking at this one? It's good?

Carer#2

Because you can actually communicate by sign language. There's eye contact. There's touch. There's picture and sounds. How, I don't know if the doctors know that these can actually help.

Supporter

Facilities. You can put wherever you want to put. OK. All right. Bad?

Service user

Bad.

Supporter

Examination, yeah? What do you think [inaudible]. Good, alright or bad?

Service user

Bad.

Supporter

They didn't treat you good?

<i>Service user</i>	<i>Not really.</i>
<i>Supporter</i>	<i>In what way, can you tell me?</i>
<i>Service user</i>	<i>Take a long time. A long time for nurse.</i>
<i>Supporter</i>	<i>Take a long time.</i>
Carer#2	Until you suffer with some kind of disability or you have relatives or friends who are with learning disabilities and you go with them, you don't know what they go through. And they are not treated very nicely and something does need to be done about it.
Carer#3	Well, I think they need to have more awareness of autism and other disabilities. And if anyone has got it then they should be treated differently, they shouldn't have to wait with everyone else and if they have to stay in overnight, then maybe they could make it someone could stay with them as well.
Carer#4	It's not always the professionals know best. It is the person themselves and the person who is looking after them that knows best.
Carer#3	That's why I think it would be very good if all the doctors, GPs, hospitals and dentists could visit all the day centres. Therefore they would be checking all the young people over and if there was any problems, they could find it out then and not wait until the problem got so severe that it was a case where they had to go into hospital.
Narrator	Looking at these experiences, it's important to recognise that this is about us all, and if we are going to make change, which we want to do, we've got to work together. And we've got to listen hard and communicate well and ask ourselves some questions about our own prejudice, our own stereotypes and how we would want to be treated within the system because if it's doesn't work for you, it's not going to work for these people in the film.