HOUSE OF LORDS

Revised transcript of evidence taken before

The Select Committee on the Equality Act 2010 and Disability

Inquiry on

EQUALITY ACT 2010 AND DISABILITY

Evidence Session No. 6 *Heard in Public* *Questions 60 - 65*

TUESDAY 20 OCTOBER 2015

4.05 pm

Witness: Mr Andrew Lee

Members present
Baroness Deech (Chairman)
Baroness Brinton
Baroness Browning
Lord Faulkner of Worcester
Lord Foster of Bishop Auckland
Lord Harrison
Baroness Jenkin of Kennington
Lord McColl of Dulwich
Lord Northbrook
Baroness Pitkeathley
Baroness Thomas of Winchester

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Examination of Witness

Mr Andrew Lee, Director of Policy and Campaigns, People First (Self Advocacy)

Q60 The Chairman: Mr Lee, thank you very much for coming. I know you have an assistant with you. We hope you will feel free to tell us what you think and feel about the law. I want to remind you that this session is open to the public and there will a webcast going out live as an audio transmission and subsequently accessible via the parliamentary website. A verbatim transcript will be taken of the evidence and put on the parliamentary website. A few days after this session you will be sent a copy of the transcript to check for accuracy and it would be helpful if you could advise us of any corrections as quickly as possible. After today, if you want to clarify or amplify any points made during your evidence or have any additional points to make, you are welcome to send in supplementary evidence to us. If those of us around the table have an interest to declare we will mention it before we question you. Do feel free to tell us what you feel about the questions we are putting to you because we value your evidence very much. Perhaps you would like to introduce yourself before we start on the questions.

Mr Andrew Lee: My name is Andrew Lee. I am director of policy and campaigns at People First (Self Advocacy) in London. I have been in the disability movement for 20 years. I have been an independent lay assessor inspecting residential homes. I would not be in a job if it were not for Access to Work. It is really important to note that part of the problem with the law is that a lot of people with learning difficulties do not know the law and how they can use it. Discrimination for people with learning difficulties starts at school. For them it is normal to be discriminated against. Today it is called disability hate crime. The people that are responsible for enforcing the law do not have the skills to work with people with learning difficulties. I think employers are frightened of asking for help and advice if they are thinking about employing disabled people. We might have the ambition to get a job but we have not got the support as we think about applying for a job. We do not know how to read or how to write, and that is our first identification of how the school system is letting us down.

The Chairman: Thank you, that is very clear. The first question is from Lord Northbrook.

Q61 Lord Northbrook: Your submission identifies problems with getting reasonable adjustments to meet the access needs of people with learning difficulties, including from Government and local authorities. Are there changes to either the Equality Act or to Government policy and practice that would address these problems?

Mr Andrew Lee: For years people with learning difficulties have been talking about accessible information and EasyRead. Today I received some information through the post from the Government about benefits. It is totally inaccessible to me. I cannot read it and neither can my wife. There are lots of changes around benefits that the Government are making but it is totally inaccessible and we do not know what is going on. We have not got the support at home for someone to read it. Even if we have, we are told by our own support, "It's not in my job description, I can't actually read it to you".

A good example is when my wife and I moved into our own home we were given a tenancy agreement. We asked for it to be in EasyRead because it was not in our warden's job description to read it to us. We had a problem and because the problem was in our home we did not know whether it was our responsibility or whether it was the council's responsibility. We had to go on a three-month waiting list to get an advocate to read it to us, which meant that we had a three-month problem, yet the local authority's decision was because we were in a warden-controlled set-up we had support. No, we do not.

When this information is going to a person with learning difficulties, everything needs to be in EasyRead as accessible information. It will save you money. At the moment, if you want information you have to ask for it. If you change it so that whoever is providing the information has to put it in EasyRead, and if you want it in jargon format you have to ask for it, it will save you money and more people will know what you are talking about and people might know what their rights are.

People do not have support and they need support. We need support to think about our options and our choices and to access services. In every aspect of our life we need information in EasyRead to have choice, control and independence so that we can make the decisions that we want to with the facts so we are making the right decisions. At the moment, unless we actually ask for it, we do not get it. I went into my local council one day and asked for some information in EasyRead. The individual was very nice and very helpful but she did not have a clue what I was talking about. Even if the council has a responsibility to put information into EasyRead, its staff do not know what EasyRead is. The easy answer is to have a strong self-advocacy organisation that can train people. We need support. It comes down to good strong support.

With regard to Government policy there needs to be proper funding, proper standards, capacity and no jargon. What might be jargon for one person with learning difficulties might not be for another and it might be support that a person needs. There needs to be proper support. The Government once said it wanted a strong self-advocacy organisation in every town and city. If the Government wants to meet any kind of ambitions it has for people with learning difficulties to play an equal part in society then there needs be a strong self-advocacy organisation run and controlled by people with learning difficulties in every town and city. Funding for those organisations needs to be ring-fenced by local authorities. People should not get consultation overload. A lot of local authorities will ask for a consultation on this or that. Over the years I have noticed that we are asked for our opinion but then no decision is made about moving forward, carrying out our recommendations and acting on our advice. Money is usually at the end of it; they have not got the money to do it. It requires common sense, time and support. With an ever-ageing population, self-advocacy organisations are going to be crucial because mum and dad and siblings are either going to be working or using social care themselves to have a quality of life. They will not have the knowledge or the support to help family members. That covers the points for the first question.

The Chairman: We will do our best to make sure that our report takes matters forward. I have to say—and I do not mean this lightly—it would be very good for all lawyers to have to put things in EasyRead, not just for people with learning difficulties. It would be an excellent exercise all around. The next question is from Lord Foster.

Q62 Lord Foster of Bishop Auckland: I have no interests to declare. You identify access to employment as a significant problem for people with learning disabilities. Can you explain what the problems are? Can these be dealt with by employers making reasonable adjustments, or is the problem a reduction in help from Access to Work?

Mr Andrew Lee: I am able to be here today because I am using Access to Work support. I get lost very easily. I have no sense of direction. It has taken me three days to prepare to meet you today. I would not have been able to do that without support from Access to Work. If a person with learning difficulties is thinking they would like to actually work, the problem starts with the fact that they have not got one-to-one support to help them think about what kind of career they would like. Everything is going online at the moment and that is a barrier for people with learning difficulties to get into the world of work. That is just one and there are others too: attitudes in job centres, at home, among the public generally. Employers have no information and they have not come into contact with disabled people or people with learning difficulties wanting to work. When I talk to the taxi drivers who take me to the train station in the morning about Access to Work they say, "Access to what?" They do not know, and I am sure it is the same for employers. If people want to work they have to have the right support and that will be very personal to them.

When we have spoken to Access to Work they do not understand learning disability at all. A work colleague has been given only 20% of the support she needs. For some strange reason Access to Work cannot understand that a learning disability does not change. I cannot understand why bright, intelligent people who are responsible for a big chunk of funding cannot understand that a learning difficulty is there for life. You cannot get rid of it. It will not change. We have tried to train Access to Work. We have given their staff training. We have worked with them on making information accessible. Then they change their staff. I get Access to Work but I cannot tell you who my Access to Work person is at Access to Work. I receive a text and luckily I can read but a lot of people with learning difficulties cannot read. They need support to read information so that they can make choices and decisions.

If you get a repetitive job, such as shelf stacking or trolley collecting at Tesco, you can learn that and then obviously there is less need for support, but for people who have ambition, who want to change their job or climb the ladder within their organisation, their job changes all the time and because the job changes the support they need changes. You need full-time support because you never know what is going to happen in the next moment. You might get a phone call where someone is asking for advice on benefits.

There was a gentleman who came into the People First office. His benefits were in a mess, his pay structures were in a mess and he had no support. When he came in we gave him information and he had support. He only had six weeks' support but the problems that he was facing were ongoing. He needed constant support to solve the problems and the support structures that were open to him within his local area just were not there. Not only were we actively helping the person who needed help, we were also advising and helping his supporter. When the supporter left our office he had learned how to help not only the person he had come in with but also the 24 other cases on his records.

I had to reapply for Access to Work. We spent a lot of time filling in the information. We sent it off. The person I spoke to said: "I get it. I understand everything. I do not need to ask any

questions at all. I can approve your Access to Work." "Great," we thought. However, there is a work colleague who does a similar job to mine but is responsible for several projects and who has a learning difficulty like I do. We used the same model, filled in the information and we did not expect a problem. But we did have a problem. It took us months to get Access to Work to approve funding for a year. A year might seem a long time in some people's books but when you are running a charity it is not a long time at all because you might have several projects that you are running and you have to think about where the next batch of funding is coming from in six months' time. We could not understand why the person who was acting on behalf of Access to Work did not understand what a learning difficulty was. We had to fight. We had to mention that we were going to be taking the information to the Minister for Disabled People. If Access to Work is going to be successful, then Ministers need to knock some heads together. They need to find out why it is that the staff they employ at Access to Work do not understand what a learning difficulty actually is.

We think that there has been a change in policy whereby only 20% of your original support package is being given to people. We have not been told about it. There has been no consultation. As soon as you mention that you have a learning difficulty you seem to be automatically pushed into a column where you will get only 20% so you are losing your support; for a lot of people can mean the difference between being in a job or not. It is discrimination. It would be very interesting to see from the direction that Government policies are going whether the Government is actually breaking law. We think they are. We think that they pay lip service to the Equality Act. Other self-advocacy organisations where they employ people with learning difficulties have had a similar experience. For a lot of us, we know that if we lose our jobs the chance of us getting another job is zero because the structures in place do not allow for a learning difficulty.

The Chairman: Am I right in thinking that Access to Work payments have been capped at a certain amount?

Mr Andrew Lee: We are not sure but we think that is what is actually happening. They may say they are only prepared to fund this much, but a lot of people will be working for small charities that are fundraising themselves. Access to Work needs full-time funding to maintain the support. Some people might think that supporting people with learning difficulties in work is an easy job, but it is not. Next to being a parent, it is probably the hardest job in the world. It is bloody hard to get good support, which means keeping good people. Access to Work needs to be properly funded so that it can keep good people. When people with learning difficulties go into meetings where they are representing their organisations, when they are using their support and they come across issues, sometimes their supporter will know when they need support and when they do not. That comes with learning how the person with learning difficulties works, takes things and acts in situations and they can identify when they do and when they do not need support. That comes with time. We think there are some internal decisions being made about freezing the funding. That needs to be investigated because, if it is true, it needs to be stopped. It needs to change.

Q63 Lord Faulkner of Worcester: I declare an interest as vice-president of Level Playing Field. I am the sponsor of a Private Member's Bill on disabled access to sports grounds and I am also involved in various public transport issues. My question is this: is reliance on individuals bringing cases to courts and tribunals an effective way of achieving compliance with the Equality Act? Could this be made easier for people with learning disabilities, and if so, how?

Mr Andrew Lee: First of all, because discrimination actually starts at school, people grow up experiencing discrimination from when they start school right through to now. For a lot of people with learning difficulties discrimination on all levels seems normal. They do not know it is discrimination when someone calls them a name or insults them. They do not know the difference between a hate incident and a hate crime. They do not know where to go to find out whether what has just happened to them is discrimination and whether they can do anything about it. The law generally is not accessible to people with learning difficulties. The support is not there. We do not know what is and is not against the law. We grow up thinking we cannot do anything about our situation, which might be completely incorrect but because there are no support structures to find out, we do not know.

When the Disability Rights Commission had its helpline, it meant that we could pick up the phone and ask someone and get some advice on what to do next. When the DRC closed and the Equality and Human Rights Commission took over, they took over the responsibility for that helpline but the Equality and Human Rights Commission did not understand the importance of the helpline to people with learning difficulties. Out of all the disability groups we are the most marginalised and most cut off from society. They closed the helpline. It was a financial decision. It was not a decision made as to whether people could actually access their rights or not. With the helpline closed it meant a lot of people with learning difficulties were cut off from access to the very organisation that was supposed to fight for our rights. With the Government closing legal aid, we cannot access the law, even if we find out through other disabled people that what has actually happened is discrimination. No citizen should ever be in that position but for some strange reason our Government seems to think it is acceptable. It is not.

I mentioned earlier that we needed self-advocacy organisations in every town and city. That can be sorted out very quickly. As to having access to the law, what might be a very good move is to have legal support in every town and city and for that legal support to be based within self-advocacy organisations so that people can go and get advice. At the moment, even if we know that the law should protect us, we do not have the funds or the capacity to take a test case. That was why the Equality and Human Rights Commission's ability to take test cases was so important. When the commission took a legal test case, because there was a self-advocacy group in a town or city, we could go to one place in that town or city and say, "The commission is taking a case against this organisation because they discriminated against this person in this way. If the commission is successful you will benefit from it because it sets an example in law". Ninety-nine per cent of information for people with learning difficulties is passed on by word of mouth. If you close down the organisations you close down the communication links that people rely on to have choice, control, independence, access to the law and access to society, and to play an equal part in society. I have all these ambitions and if I have support then I might have a chance of actually reaching those ambitions. Without support I am stuck at home, isolated, cut off from society and the law.

One thing that might be really good would be, let us say, that a test case is taken and, whatever the decision, whether it is good or bad, there is a requirement for an organisation to have the staffing capacity to go and talk to people with learning difficulties by word of mouth, to bring people together in their local community, to talk to them about the case and how it might benefit them. It is two-way because people can say, "This is my experience. Am I protected and can I get support from the law? Can I do something about it? How do I get support to take a test case?".

I had left the office and gone for lunch one day and I was kicked, punched and spat at by a group of youths. Most people would be able to undertake an ID: how tall were they, did they have blue eyes, what clothes were they wearing? Because it happened so fast I could not do that. All I knew was that they had jeans, trainers and t-shirts, but it was not enough for the police. From our experiences we might use language like bullying, but what has happened to us is that the law has been broken. The only people who can tell us that are police officers.

One good thing you could do is make sure, by having a self-advocacy organisation in every town and city, that there is a requirement for a working relationship with the local police force so that people with learning difficulties within the local level can train police officers so next time they come across hate crime, police officers will know how to work with people with learning difficulties if they have been a victim of hate crime and will be able to take it from that point to the courts to see the people that have discriminated against them charged and prosecuted. Disability hate crime should have a mandatory sentence. For example, if someone kills someone there is mandatory 30 years' sentence. For hate crime there needs to be a mandatory sentence in order to build confidence in the system so that people will use the law. No one has confidence at the moment to use the law.

The Chairman: Can I go back to something you said about the helpline? Are people with learning difficulties aware that the helpline has been replaced by an outsourced Equality Advisory Support Service helpline?

Mr Andrew Lee: No, to put it simply. That is the Equality and Human Rights Commission's fault. One of the reasons why the helpline was successful when the DRC was running it was that they went into every town and city and spoke to self-advocacy organisations and told them about it. They had a card and it said, "Here's the telephone number: if you have a problem, use it". The commission closed down the helpline and they stuck the replacement on the website. However, one of the major problems that people with learning difficulties have is access to social media. How do I go on a website? I need support to use a computer so putting information as crucial as that on to a website is a bit like whistling in the wind, sending a bird off and hoping that will it fly in the direction that you want it to. I am very angry about how the commission dealt with the helpline.

Q64 Baroness Jenkin of Kennington: I have no relevant interests to declare. Perhaps I may say how much we all sympathise with your point about inaccessibility particularly to benefits information; it stands in contrast to the clarity of your evidence. Your submission is critical of the Equality and Human Rights Commission and argues that there has been a loss of confidence in it by disabled people. This follows on from what you were saying. Are there any specific changes to how the EHRC works that you would like to see that you have not already told us about?

Mr Andrew Lee: Because the Government cut the funding of the Equality and Human Rights Commission, they made a lot of staff redundant and their capacity to do crucial pieces of work was lost. There are a lot of dedicated individuals within the Equality and Human Rights Commission but because of the cuts the commission no longer has the capacity to meet its legal responsibilities.

When the Disability Committee started to work with the wider commission, we were asked for advice on other equality areas. The capacity of the Disability Committee to focus on disability issues was extremely hard to fulfil. We could not tell disabled people what they were doing. For example, if you lived in Cumbria, or anywhere else in the United Kingdom, you did not know what the Disability Committee was doing. In the DRC days there was a person who went on TV and told people what the DRC was doing. So even if you did not

know about the Disability Committee or the Disability Rights Commission, you recognised that person, and you knew that one person was representing the Disability Rights Commission. The Equality and Human Rights Commission did not have that and relied on sending press information out.

We were not able to work effectively. It took the commission four years to understand my access needs. If the Equality and Human Rights Commission had difficulty meeting the access needs of one person, how are they capable of meeting the needs of 2 million people with learning difficulties? How can they do that? It is about accessibility. When they set out the public sector duty responsibilities, the single equality duty, I asked how people with learning difficulties will know who the contact person responsible for equality is in that area. The person I was speaking to could not give me an answer. That is very worrying because people with learning difficulties deserve better. They need to have confidence that if they are making choices and have control, they will have support and a body that is acting in their best interests if they cannot.

One thing that you could do is look at whether there needs to be a disability equality duty that is there and in force. Each local authority would have to say, "In the next six months this is what we are going to do for people with learning difficulties and disabled people in our area. We are going to bring them all together and we are going to tell them what our plans are". Disabled people in that area can say, "Yes, we agree with that", maybe by setting up a disability panel that local authorities can refer to, supported by self-advocacy groups, to help them with every decision that they make that will affect the lives of people with learning difficulties around housing, health, choice, control. That body, with the right support, can feed back to self-advocacy groups in their local area and say, "In the next six months this is how we are going to work with local councillors and the local authority", and put in some accountability. Hopefully councillors will benefit from that. Councillors will learn what they are doing right and what they are doing wrong and if they are doing something wrong there will be a map that people with learning difficulties have rolled out about accessible information, all the issues they have, to help make local decision-making accessible to them.

With funding, there are lots of people who are responsible for making decisions about contracting. People who are responsible for rolling out contracts need to say, "We need a disabled organisation in our area that will help us achieve some of the responsibilities that local authorities have around improving the lives of people with learning difficulties". That is a suggestion. It might be politically difficult but it will mean that people with learning difficulties will feel as though we are not just being listened to but our advice is being taken on board and we are part of solving the problem, not just telling people what the problem is.

Q65 The Chairman: As they say, some people bring us problems and other people bring us answers. Any other comments around the table?

Lord Harrison: Are there any examples of what you have just described currently operating?

Mr Andrew Lee: In my local area there is a structure called the partnership board and it brings together disabled people, family members, carers and people who are responsible for making decisions. A lot of what they talk about is to do with the issues that people with learning difficulties face, not just at a local level but at a national level, too. They actively work on solving local problems with local solutions. That means people with learning difficulties are talked to. They have asked the local self-advocacy group not just to worry about the north of the county but to cover the whole of the county. Cuts in local authority funding have led to the closure of groups or a reduction in services, therefore a lot of people with learning difficulties no longer have access to self-advocacy organisations. With hate

crime, they had a local telephone number and they got all the local businesses and the railway station to put up a helpline number so that if there was a problem it could be used. That was a local solution to a national problem on hate crime.

For people who had had experiences with hate crime they developed training and they worked with the local police on hate crime and all of that went through the partnership board to make sure that not just the people in the self-advocacy organisation knew about it but parents knew about it as well. I am sure that there are local solutions but you need a strong self-advocacy organisation to work with. I would suggest that you say it is absolutely necessary that every local authority funds a self-advocacy organisation properly for the lifetime of this Parliament, to begin with, and then local authorities can learn what they are doing right and what they are doing wrong, but also have structures within local hospitals and wherever there is a public service. Health professionals need to be trained by people with learning difficulties. If you are an employer and running a public service, whether that is the police, the health service, GPs, they need to see whether their training actually meets the expectations of people with learning difficulties at the moment. If it does not, they need to say to the people who are responsible for developing the training that they will need to work with people with learning difficulties to develop training. If you are a health professional you can say, "I remember a person with learning difficulties told me this in my training and now it is actually helping". That is especially relevant if you have a learning difficulty and a mental health problem because one thing that we find is that if you have both you will swing from the learning disability service saying, "Yes, you have a learning difficulty but we do not know how to deal with your mental health", and the mental health service saying, "We can work with your mental health problem but because you have a learning difficulty we do not know what to do". We need joined-up local decisions about learning disability and mental health and to identify the organisations around that work at a local level and have a local/national structure.

The Chairman: Mr Lee, you said you spent three days preparing. I have to tell you it was very well worth it. Your evidence has been so helpful and really impressive and we will certainly take on board all the ideas that you have given us. I think you have made a lot of things plain to us that perhaps we suspected before but now we really know and your advocacy has been really effective. I want to say thank you very much on behalf of the whole Committee. We shall do whatever we can to resolve the problems that you have raised. Thank you very much for coming to see us and all the time you have put into it.

Mr Andrew Lee: That is okay. I know that you have read lots of information that has been sent to you. One question that Self Advocacy in my local area have asked is what will be done with the information—the consultation—that we sent to you, once it is read?

The Chairman: What you have sent us will go up on the website and we will consider it all and feed it into report that we make. Every single page of every single submission has been read. It is not wasted at all. Thank you very much, and thank you to your assistant as well.