

Hammersmith & Fulham Disabled People's Commission

Thursday 16 March 2017

CHAIR: Okay. We are ready to go. All right, welcome, I'm sorry we are late. We will do our best to try and catch up as we go. So, I don't know if anyone has noticed, there are lots more people round the table than usual, because we have DeafPLUS with us and we also have a big contingent from Safety Net People First. What we will do, I will say a couple of things once we have gone around and introduced ourselves about the Commission for people that haven't been to a Commission meeting first, but I will keep it short, so that we get down to the business of the meeting. I'm going to check with Peter and Fawad that the fire alarm isn't likely to go off.

NEW SPEAKER: No test.

CHAIR: If the fire alarm does go off we have to leave the building. Shall we go round and those of you that are commissioners, can you say that you are, so that we can work out who the commissioner is and isn't I will go first, I'm Tara Flood the Chair of the Commission.

NEW SPEAKER: I am Patricia, commissioner.

NEW SPEAKER: Ramona, commissioner.

NEW SPEAKER: My name is Sue, cabinet member for social inclusion and I am here to support you in the commission's work.

NEW SPEAKER: My name is John, I am a Safety Net People First member, plus I am the representative for the partnership board for Hammersmith and Fulham and also, I am the treasurer for Safety Net People First.

NEW SPEAKER: My name is Gwen Pressly, I come from, I come here to complain about Hammersmith and Fulham.

NEW SPEAKER: My name is Mary Hicks, I am from DeafPLUS and I am manager.

NEW SPEAKER: I am Kate, commissioner.

NEW SPEAKER: I am Victoria, I'm a commissioner and Chair of Action on Disability.

NEW SPEAKER: My name is Ali, and I am here as deaf commissioner.

NEW SPEAKER: Hello, I am Faisal, I am a Safety Net People First member, and I am also a trustee of Inclusion London, and what else? Partnership board representative for Hammersmith and Fulham, and I think that's it.

NEW SPEAKER: Thank you Faisal. My name is Martin, I am one of the commissioners. I also am a member of the Safety Net People First, and the chairman of Safety Net People First.

NEW SPEAKER: My name is Sheryl, PA for Safety Net People First.

NEW SPEAKER: My name is Peter, I'm a support worker for Kevin Caulfield, who is the officer.

NEW SPEAKER: I'm David, I am a commissioner.

NEW SPEAKER: I'm Jane, I'm another commissioner.

NEW SPEAKER: Peter Smith

NEW SPEAKER: Fawad, policy and strategy team.

CHAIR: I asked Peter to come along because he has been helping us whilst Kevin hasn't been well, to plan the public consultation event. Usefully, I spoke to Kevin this morning, and he is on the mend, he says hi to everyone, and I have already got him signed up for doing something at the public event in April, which we will think about, and he is slowly returning to work which is great news, so no doubt we will see him at the next meeting.

So just a couple of things about the commission for people that are here for the first time. The disabled people's commission was, we started last September, and announcement about the Commission was made by Steve Cowan, leader of the council the previous December, so December 2015 on international day, and we are one of the residents committees, residents commissions that was set up by the council -- there has been one on air quality, one on poverty and worklessness, one, a business commission and I think one on Heathrow? I think there was.

NEW SPEAKER: Peter. And one on air quality.

CHAIR: The idea about the Commission is that we are resident-led. And Steve asked me to chair it and I said very happy to and we would like to,

the Commission will be all disabled people, and to try to, because we only have 15 months to do our work, we decided that it would be too difficult to try to think about all of the priorities that were important to disabled people, so we decided to think about what would be the most strategic thing for us to do that would have a lasting change, so we decided that we would work out how we can make sure that disabled people are involved at the beginning of decision-making and policy-setting within the local authority. The posh word for that is co-production, but what it really means is really partnership working between the local authority and disabled people so we will be reporting, putting out a draft report in the autumn, with full publication early next year because we are very keen that some of the recommendations that come out of the report will feature in the political manifestos for the local elections which are May 2018. So we have got our work cut out.

We are also trying to do some piloting of co production and we are hoping that the first one for that will be housing. We will get on to that later on the agenda. I'm not going to say any more than that because we have less time than we hoped. So, can we look at the minutes, 22 pages of minutes. I have shortened mine down to about 6 pages. First of all, can I ask those people at the last meeting, do they look like they are an accurate account of our discussions on the 1 February? I will get back to matters arising.

PATRICIA: On page 10 I read it as something I said, and when I read it it doesn't make much sense to me. Would it be possible to change the wording?

CHAIR: Do you have a different type of wording that you would like to use? Is that your replacement? (hands to Tara)

CHAIR: I will have to find that, but if I take that and that is your change that you want to make.

PATRICIA: They might not understand, they might think I'm saying you have to repeat something 20 or 30 times when in fact it is the limit that you can repeat.

CHAIR: I have just spotted it. Okay. Thank you for that. Anyone else wants to make any changes to the minutes? I will take that as a no, which is great. And shall we go on to actions from the minutes. I

highlighted the ones that we need to consider. The first one is that Kevin was to contact Lee Fitzjohn the head of insight and analytics, that is information and statistics, but Lee is on longterm sick and I think the conversation that Kevin had with someone within that team, they are the people that are helping us do the survey, I should have said, I am hoping that a couple of people from that team will come along to the next meeting because by then the survey deadline will have passed. They will have started to do some early analysis of some of those responses. I think Kevin is going to organise that in the next few days. If I say anything that sounds strange or wrong, I'm going to rely on you to wave your hand of something.

NEW SPEAKER: Peter. Yes, that is quite correct.

CHAIR: Milan has been incredibly helpful over the last few weeks. On the next page, draft strategy on tackling social isolation and loneliness to be brought to the next meeting, so paper has been circulated...

GWEN: I haven't received the survey, haven't received anything at all about the survey.

CHAIR: I met with Ali before and he is going to circulate it.

GWEN: I have no idea.

CHAIR: That is really helpful, we will make sure that you see the survey. The closing date is not for a while yet, so there is plenty of time to complete it, but please I really urge you to send it to as many people that you know to complete it. Although we know lots of disabled people don't feel they are involved in decision-making, it will be great if we hear from lots of other Deaf and disabled people that that is true, so we will make sure that you get that, hopefully tomorrow. Okay. Back to the tackling social isolation and loneliness. The executive summary was sent round to everybody last week, Peter, so just...

NEW SPEAKER: Peter. It was Monday.

CHAIR: It was Monday, so it is quite a short time before the meeting. I propose that if we have time at the end of the meeting and people feel they have had a chance to look at it, let's talk about it, but if not let's have it on the agenda for the next meeting.

NEW SPEAKER: Faisal... Martin can't find....

CHAIR: Last meeting we talked, the Council is putting together a strategy

to tackle social isolation and loneliness. They have written a draft plan and it has been circulated, but it was only circulated to us on Monday. So what I'm saying is if people haven't had a chance to look at it and people might not have done, then we can still have a think about it at the end of the meeting and if we need more time, we can look at it at the next meeting in April, because there was also another shorter paper, a one page paper, it was sent round to everyone yesterday, so too tight to have a conversation.

GWEN: What is the topic of that paper.

CHAIR: It is implementing Hammersmith and Fulham social isolation and loneliness strategy. Susie reminded me, because we are a big group tonight, whenever anyone talks, can they say who they are, before they say anything, just for Palantype and no doubt for the interpreter too. So, back to the actions. Social isolation strategy. I don't know which page it is on the minutes because I shortened my documents but there is an action about commissioners committing short biographies to Kevin. That has happened, I know, I know we are needing a photo of Ramona, I will talk to her about that in the break... I think we have one of you, Martin.

NEW SPEAKER: Peter: Not on the web page.

CHAIR: We still need to get you too, Martin. And we are just waiting for I think it has been the photos and biographies have been put up on the draft page, not live yet because I have been sent the link, so I will look at that tomorrow and hopefully that can go live in the next few days and we will just have to work out how we get a photo of Martin and Ramona. It may well be that either of you could send one.

RAMONA: I can send one from the Mayor's reception.

NEW SPEAKER: Peter. We can use that for Ramona, yes.

CHAIR: Have you got a lovely photo that you can send that will go on the Hammersmith and Fulham website for the commission page?

MARTIN: No I don't think so.

CHAIR: We will think about how to get one. I can take one with my phone, or someone who is a better photographer.

NEW SPEAKER: Faisal: I think Safety Net has got some pictures.

MARTIN: Safety Net might have some photos, yes.

NEW SPEAKER: Faisal. He has done some police training.

CHAIR: If you find one please send it. Are you able to email it.

MARTIN: That is not a problem.

CHAIR: Henrietta from Inclusion London, presentation to be sent round to commissioners, that happened a couple of weeks ago. Then under any other business Tara to meet with Bathsheeba from the HASCSI PAC health and adult social care committee, I have not had a chance yet. I will follow up in the next week or so. And I think that is all the actions that I have spotted.

So today I'm really delighted that we are going to have 2 really good presentations, the first is from DeafPLUS, and from both presentations what I have asked is for both organisation to talk about how they think deaf and disabled people with learning difficulties feel they are included in decision-making and policy setting in the borough at the moment, and I'm happy for you to be as honest about that as you want to be but also really keen to hear from you what you think would be the solution to that, so how can things be improved? And what advice you would give the Commission for the recommendations that we are going to put together later in the summer? Does that make sense... ?

MARY: I think so. I will start with my presentation and then any questions, please ask me at the end of the presentation. It should be clear, hopefully. Thank you so much for inviting us here, I'm so happy to be here. Hopefully, we are going to start with something that can carry on into the future. I'm going to give you a brief explanation about DeafPLUS and advocacy and the services we support. We want inclusion for deaf and hard-of-hearing and for blind and for Deafblind, and for everyone to be included. We really want to use one of our specialised services and the aim is to remove barriers, that is including deaf and Deafblind, and try to access services without the barriers being there. So, we are trying to remove it so that we are completely accessible. The other thing is our staff are all deaf, so there is no communication problems. We also have interpreters that come in and also communication support workers so they can communicate with hard-of-hearing people, so no communication barriers with us at all.

DeafPLUS is based all around the country. The services are similar, some might possibly be tweaked, but the information and all the advice is on the services. For some background, we support people that have been deaf in Fulham for over 15 years, but the funding very sadly was stopped. I think that was round about 2015. Also, having said that, we are still receiving some element of funding and that is how we are using volunteers to support our services in Fulham and the needs that are there are very varied. It might be, for example, making phone calls, filling out forms, trying to take some letters, possibly, explaining their rights to them and the access that they can get to services and what they can and can't do. So really, that is the services.

I would say we have on average 30 clients over a period of about one year. I know that sounds quite small but the funding we receive matches the clients. It is small, which also doesn't give us much time to have continuity with are clients, so we meet people. That sometimes has to stop, we get the funding from there and that supports that person, then we have to focus on another area of funding and it is horrible having to say to clients "I'm sorry, we can't support you," and we have to refer them to Action on Disability. So that is what we are trying to achieve but it is quite difficult. We are experiencing communication problems.

Right, okay, they might arrive somewhere for access to service and they are told they are going to have a interpreter booked and they are told it is 2 weeks time! So that person is getting frustrated thinking they are not going to have a interpreter there for them, that can be a big problem. Book an interpreter is no problem, yes, but that person does have to have some concept of deaf issues. They need to be able to understand whether someone is deaf or hard-of-hearing, how it affects them, all those problems. They need to be fully aware and are often not. But in DeafPLUS, we know. We can empathise and we can support in a better way. People often arrive to come and see us, they have a letter, they panic about it, don't understand what is happening, who will help them. So they come to us and we reassure them they don't need to worry. It is just a general letter, it wasn't anything of any relevance. So if they didn't

have access to our service, they would be running around feeling stressed and unaware of what was going on. I have got so many examples from their feedback, but every slide in this presentation we don't have time to go through all of them, otherwise there would be a mountain of them. But I'm sure I speak for Gwen and any other deaf people, that I can be aware of deaf situations. About 2 years ago, this gentleman lived with his mother in this area, and his Mum passed away. He had the expectation that he would be able to stay in the flat and he had no idea what was happening, he didn't understand the process. And he had no idea, he was asking for help, he had to ask his hearing sister and his sister worked full time, how could she assist him? So this was more stress for him. He didn't know what was happening, but the end result was that he had to move out of the flat. So the back story is the access to information. That deaf person doesn't have to go through that torment. Also now, there is lots of benefit forms and we know all of us know that they have been changed recently. How do you get access to information? We have no idea. Why has it changed from DLA to PIP, what has happened? You know, I thought this was going to go on for life. Now they didn't know that they had to inform and go to different places and ask for help on how to complete the forms. I would like to give you more information but unfortunately there is not enough time to collect all the information and distribute it all I'm afraid. So, that is our DeafPLUS service in the Ealing area. And we have access to information at any time, it is a drop-in centre, you can be referred, you can come and visit us if you have problems, exactly the same for a hearing person. You know, if they had an issue they would turn to someone for advice. Obviously we know that they can't do that and that makes them feel very, very unsettled. That is it, thank you. (applause).

CHAIR: Gwen, are going to contribute as well...?

NEW SPEAKER: Can I ask the question now.

CHAIR: Could you hang on and we will hear from Gwen and then have questions after. Over to you, Gwen.

GWEN: I will start where I live now in Acton. I had the drop-in centre with

DeafPLUS, it is very close to my home and I went through and I visited and they were very helpful. And it changed from DLA to PIP and it was very helpful and they really helped me and I haven't received any help from the council. DeafPLUS supported me for over 15 years, and that was my background and I hope when I move it the support will be continued, and I felt very comfortable with the service that DeafPLUS provided. 2 years ago, I went because I had a problem with my husband and I realised that they had stopped their services and I was disheartened. I went to council at Hammersmith and Fulham and there was no interpreter available and no access I didn't know what to do I didn't know what was going on, I didn't know what to do. The services from Hammersmith and Fulham said that they would come to my house for an assessment. That was done, I accepted that. So Thomas - he was a diabetic, type 1, - and that was it, they couldn't do any more, they told me we had letters from the hospital to say he had diabetes, we couldn't phone the hospital, we couldn't ask DeafPLUS to phone the hospital for us. We went to the Hammersmith and Fulham to make an appointment, there was no reply from the council. And we couldn't wait until Monday, opening time for the council. I didn't want to hassle anyone else to help me. I didn't want to hassle any of my friends or family, because they were working and most of them lived elsewhere. So later, they said they were going to come tomorrow and I said no, I had already arranged my plans for tomorrow, I couldn't do it the next day, and that happened twice when something has been arranged at the last minute and I have not been able to make that meeting, if it is at the hospital for the diabetes, very very difficult. And the hospital asked me to go every day, because I had a bad knee. There was no service there, so I couldn't go. I was trying to find help so I went to a drop-in centre to see someone there, but there was no one there to support me or help me. They maybe had another client, so I asked Clive Robinson, and there was no one to help me at all, no services at the hospital, there was nothing, there was no help. I was so stressed, the whole week there was no one to help me. And now I'm having problems with my memory, so I need help so I am waiting for someone else to come to my house, but I don't know when. I am very happy with the service that DeafPLUS provided. They

had continuous service that I could drop in, now there seems to be no one or no service available.

CHAIR: Okay. Thank you very much, Gwen. I am sure there will be lots of people with questions. David, can we start with you.

NEW SPEAKER: David: First for Mary, you said you have a mountain of examples. Are there any particular examples that are more common than others or are they just a varied selection of examples that you have? What is the most common problem that you have.

MARY: The main issue I would think is the communication problem. The access to information so (noisy plane flying overhead). So the access to information, and there is a communication barrier there, it is not accessible to deaf people. That is the main issue I would say. The other issue, most deaf people, they have their reading level is probably slightly lower than one would expect. They can pick up maybe one or two, 3 or 4 words out of the letter, but they won't be able to read it fully and understand it completely. There might be 4 letters and panic that the 4 words that they understand is something about money, or something linked to housing so they see money, housing, they see problems and it could be how to afford or where to go if you have money problems, but they see the 3 or 4 main words and get really emotional. Who am I going to ask for help? So it is really a communication barrier.

NEW SPEAKER: David. When you say communication, do you mean having a interpreter available to find what is in front of you or what you need to understand or is it something else? Could you clarify?

MARY: That is fine. Communication, the barrier of communication, maybe needs someone there who is able to sign to explain, either face-to-face, maybe an interpreter, I mean I don't think that that would be the answer, because you are not going to have a interpreter on the reception desk 5 days a week, 8 hours a day. So it makes sense maybe to have someone who can sign within the Council, find out what the problem was and how to solve that problem. Maybe, for example, form filling or someone calls to make an appointment for the hospital. Interpreters are great! But the interpreters is only a voice and a communication aid between sign and spoken. They won't make sure that that service user actually understands what is being said or done,

how to answer the words correctly. They might ask a question and a deaf person might say: Yes, yes, I completely understand - but really do they actually understand? So you need a specialist advisor to be able to read those lines so the service users actually understand what is being written in that form and understood. Does that answer the question?

NEW SPEAKER: David: Does that apply to what Gwen said when she says that there is no help?

GWEN: When I was at the hospital, I couldn't read the information I was given, I couldn't read the menu. So they asked me in the morning what would I like? I needed a support worker to help me with the doctor, I didn't understand anything that was happening, it was very difficult to understand, so I had to keep going there every day to look after my husband, and I was stressed.

NEW SPEAKER: Ali: Question for Mary... a question to Mary from Ali. The Council here at Hammersmith and Fulham, did they fund the services, so there was a budget for interpreters and services, things like that?

MARY: Hammersmith and Fulham the funding that we received would provide information and advice services, not for interpreting provision, so form filling, they want to have what they have access to, they want to have information on that. They want to know when they receive a letter, what is the process, answer that, what is going to happen. Before when we had the old DLA, they would come to us and say, "There is a problem with housing." And they would try and contact housing but being ignored, so we would make sure they got a phone call so we could chase things up for them. So we can have access to the right levels of English. Even the most basic thing, going to the front door, pressing an intercom button, we can't talk, we can't hear.

ALI: You closed down, what was the funding? Did you fight for that funding?

MARY: That was about 20,000 pounds, but that is only a small amount of money. So when my senior manager applied for funding for this certain project and the project was called "Living with a hearing loss" people didn't know how they would need to plan for that, how they were going to cope or learn, what equipment they might need. Can they lipread? All those kind of issues. That funding was there, but then because we had

that that specific project, we can't take funding from a different project and use for a different service. This funding is equally as important to this funding, it is a difficult balancing act.

ALI: You have 2 different partners, it is difficult. Thank you.

CHAIR: Can I steal a question because we have had quite a short period of time tonight, would you be happy if commissioners could have other questions for to us email you those questions?

MARY: Oh yes of course, absolutely fine, email me any questions at all, I'm happy to respond to anything.

CHAIR: Also the survey I talked about before, are you able to circulate that to any deaf people that you know in Hammersmith and Fulham? The work we are doing is only in Hammersmith and Fulham at the moment.

MARY: That's right, I understand that, that is fine. Email me, and what I have I will send at to you. And you can forward that on and they can forward to their friends.

CHAIR: I'm sorry everyone we are having to sort of cut it short, but Mary agreed to take questions after tonight which is really helpful.

NEW SPEAKER: One quick question: The funding issue. I will investigate. I can't remember what the issue was, but according to the website we do still fund, so there's obviously some misunderstanding somewhere around that, so let me get some clarity on the funding. And I will get back to to you:

MARY: The funding that was stopped?

CHAIR: Sue was saying that she is going to seek clarity because from what she could say DeafPLUS do receive a small amount of funding, and Mary is checking with Sue if that was for a project called "Living with hearing loss" -- is that right?

NEW SPEAKER: Sue: In the back of my mind I seem to remember there was something about the service moving to another borough, maybe Jane can help.

JANE: Question is are you aware of the statutory information standards that came into force on 1 August 2016? It is very important that every deaf person actually applies, tells the GP, tells the hospital, that they have communication needs and they have information needs and that

the hospital must comply. Everybody is collecting evidence. If you have evidence that the hospitals are not complying or the GP practice is not complying could you send it to Action on Hearing Loss, because they are collecting information. The DoH are very keen to find out what works and what doesn't work, so really important to get that information into Action on Hearing Loss. There is a questionnaire on their website, I believe.

CHAIR: That is really helpful, lovely. Thank you very much, Mary thank you and Gwen, for your time. And looking forward to receiving your completed survey. Gwen and Mary are going to leave us now. How are people feeling about going straight in to the next presentation? Have people got the energy for that. If people need to get up and get a drink, please carry on and do that. We will have a break after Safety Net and People First presentation, don't forget, I think I said a 10 minute presentation and then questions and answers. I am looking at you, Martin.

NEW SPEAKER: Faisal. We will be done in 5.

CHAIR: I like your work, Faisal.

MARTIN: Maybe a bit less, because we are all professionals.

CHAIR: Who is leading on the presentation?

NEW SPEAKER: Faisal. I'm starting.

CHAIR: John, are you assisting? Shall I hand over to you.

MARTIN: Right. It is Faisal will deliver the first bit. I will deliver the second bit and I will leave it all up to John. And then Faisal again.

NEW SPEAKER: Faisal: Okay. I don't need to introduce myself again, do I? We have been asked to talk about how people with learning disabilities are involved genuinely in decision-making and policy setting. They are not! We don't think they are, really, not in this borough. There are forums and groups like National People First and Advocacy forum. These groups ask us for our views and feed them back to the decision-makers.

MARTIN: Thank you Faisal. Safety Net People First is a disabled people's organisation run by people with disabilities or difficulties, whatever way you want to put it, and for people with learning disabilities. And I will hand you a few papers while I just go on. We provide the

following services which are talking about learning difficulties, learning about disability awareness professionals, there is the easy read service, which is to make things like this in easy read with pictures and words; the self-advocacy meetings for people with learning difficulty and training for self advocacy, speaking up training. I missed out number 4, sorry. Social events, ie, the social lives and the funky nights, it is a night club for disabled people and we just opened it a bit wider, so it is for everyone and...

JOHN: And it is opening tomorrow.

MARTIN: And if everyone wants to, they are welcome to come down to Hammersmith club, Rutland Grove, from 6.30 to 11.30, and you are all welcome. If you turn over your pages, you will see the aim, our main aims are to make sure people are in control of their care needs and support and to make sure people are alert and active. And to make people, make sure people are happy and included, or not isolated, sorry, thanks John and Faisal. And to make sure people are active in their community.

JOHN: My bit. For people with learning disabilities do they have a voice in the borough? No. But we sit on a number of groups, forums and boards and campaigns to make sure people with learning disabilities have a voice. For example, housing. Safety Net People First, sit on the housing sub group that Hammersmith and Fulham board set up. Commissioners and counsellors sit on that group as well. We have done training for housing officers to make sure that they understand our needs. We think that disabled people should be at the meetings with - [inaudible] and more involved in decision making about disabled housing. About service, we want improved health service. Safety Net People First sit on the health sub group that Hammersmith and Fulham board set up. Safety Net People First also sit on the learning disability health steering group which Peter Beards, the senior commissioning learning disability - manage this group. Safety Net People First are involved with HealthWatch and attend the NHS England learning disability and autism forums.

NEW SPEAKER: Faisal: Safety Net People First also go out in to the community, like on 7 March we went to the benefit cuts March in

Westminster which was really enjoyed.

MARTIN: We loved it!

NEW SPEAKER: Faisal: On 4 March we also went to the "Save the NHS" march, which was great, I didn't go personally but I was told it was great. And over 2016 we were involved in the disability hate crime awareness week. We think being involved in other DPOs networks is important to have a strong voice. Safety Net People First work alongside local DDPOs, we have a DPO network in Hammersmith and Fulham that meets regularly. We work with other DPOs across London on issues such as disability hate crime. We are working with Inclusion London at the moment, which I am the trustee of, to develop our independence and achieve our aims and objectives, which are in front of you. We do not think people with learning disabilities have much influence on what happens in this borough. This is why Safety Net People First exists! Thank you very much people!

MARTIN: Thank you Faisal and thank you John (applause).

NEW SPEAKER: Faisal. Thank you for listening.

CHAIR: Is that the end? Can I start with the first question, David next. I am really interested in what you said, John, right at the beginning. You asked the question that we asked you: Do people with learning difficulties have a voice in the borough? You said no. Even though you are involved in lots of things, I wonder why that is. Do you think all those different forums and boards are just not working? Is it that.

JOHN: I know that I came with you in the bus about the voting.

CHAIR: Getting disabled people to vote for the local election.

JOHN: I was screaming my voice off outside with the microphones and in the van from Hammersmith to Fulham, and I heard someone on the street saying to me "Speak up!" and then I had to speak up quite clearly, and it was quite funny, wasn't it, and then we ended up in North End Road. And we had quite a lot of people to come and see us, didn't we.

CHAIR: You were telling people about why it was important to vote, particularly disabled people. What do you think needs to change then, for people with learning difficulties to feel their voice is being heard?

JOHN: I think because I know like next year there is the General Election.

CHAIR: Local election.

JOHN: Yes, 2018, and I think people with learning disabilities should vote, get the vote in to get their voice heard, but if people with learning disabilities don't vote, they won't have a voice or a vote.

CHAIR: That is a very good point. Faisal, will you answer that question.

NEW SPEAKER: Faisal: When we were talking earlier, John did say that it felt like a waste of time with all the boards and all that, all that breathing hot air and not seeing any big changes, you know what I mean? Even though they are little changes, it is not like monumental. Like for example, when we went to the march, it didn't feel like any of the people in the Parliament were actually watching and they were going "Oh my God! ," it didn't feel like a big change, but I thought it was.

MARTIN: Trust me, it was.

JOHN: For me it is not, because I am really upset because my disability living allowance has been cut from a chunk to a little bit. And the amount of money I am getting now, I can't live on. And my card the amount of money I am getting now, I'm scraping through and sometimes I don't eat, sometimes I don't, I am not really a person to - I can't even live on the money. And I am going to the, like of a morning, I'm going to the job centre and I'm going to tell them face-to-face why has mine Disability Living Allowance been cut from a chunk like to that bit... ?

CHAIR: Lots of disabled people are in a similar position, John, you are right.

JOHN: Because my civil liberties have been cut quite a lot and it is affecting me because I am on my own, I pay for Sky, I pay electric, I pay for gas, I pay for TV licence, I pay for water, I can't, I can't do any more, it still won't be living.

CHAIR: It is a terrible attack on disabled people, it is, for sure.

JOHN: It is because it is not really fair.

CHAIR: It is happening across the country.

JOHN: Even the job centre, all they think about is themselves. They don't think about us. We are important also.

CHAIR: You absolutely are, you are absolutely right. I am going to get other people to ask you questions. Is that all right.

NEW SPEAKER: Faisal. That is despite the 7 March March.

CHAIR: I know David and Ramona have questions. David has a question.

NEW SPEAKER: David. You actually asked the question I wanted to ask, but I didn't actually feel you got an answer. When you say that disabled people are not represented, and you say that you are on the disability housing commission, health sub commission and the steering group, are you saying then that your input hasn't had an effect? I mean I understand you are complaining about the disability cuts, I agree one hundred percent, but that wasn't the question. Are you saying that being on the Commission, on the various groups and forums, isn't having an effect?

NEW SPEAKER: Faisal. I think what is being said is that we feel that it is not having an effect, even though there is like minute changes, small tiny changes in, you know, but it is not happening fast enough but not happening dramatically enough and not is not having like a big effect.

NEW SPEAKER: David. Not having enough of an effect.

RAMONA: Going back to voting, it is awful having a learning disability and a visual impairment when it comes to voting and we can't see the voting papers, when you go to vote they tell you no, we can't help you to vote, so half the time there is a lot of people that do not vote because you cannot get the help if they want to go to the voting station, if they don't want to vote from home.

NEW SPEAKER: Ali: It should be in big print.

RAMONA: It is not only that, there is people that don't use print, they use Braille or audio, so there is a wide range of...

CHAIR: Absolutely true.

PATRICIA: Listening to DeafPLUS and listening to you, clearly absolutely comes across as communication problem, between your group and the Council. So what do you want the Council to do? Because clearly there is something missing out, the Council is very much focused on local issues, so there has to be something that is not being picked up, and to me it is communication. I was wondering if you can say to me: This is what the council needs to do, this is what counsellors need to do to make life easier.

NEW SPEAKER: Faisal. We feel that what council needs to do is listen,

because we feel that we are telling them what we want but it is not being listened to, and implement it like when we say we want or we don't want the benefit to be cut and it gets cut anyway, it feels like okay, we will put it into consideration but we will do it anyway. You know what I mean. I don't know if benefits or stuff like that actually affects the Council. I mean like are they part of it or something? I know DWP is part of it, but I don't know if the council has any effect on it or not. But you know like things like that.

CHAIR: That is a good idea. Jane and then Ramona.

JANE: I would like perhaps you might like to respond....

NEW SPEAKER: Sue: I hope that you received in the last 2 and a half years a completely different approach and an opportunity for people with disability, living with disabilities that we as the administration are absolutely committed to ensuring that you do have a voice and I hope that you will have seen some improvements. However I completely understand that sometimes what you haven't got is an explanation as to why something can or can't be done and I think often, communication, it is a 2 way thing so I think what we are saying is we want to hear your views and we want to know how we can improve things for you. The Commission is tasked with trying to make this the best borough in the country to live in if you are living with a disability. However, I think sometimes it is about the explanation. So when you asked about DWP, which is absolutely right, the DWP is run separately from central government and we have absolutely no opportunity to change that. But together, we could campaign to get things changed at central level so I think often some of the questions that you want, some of the things you want to know about you are not getting an answer and I think that is definitely something we need to improve on because we need to be open and honest and clear about what changes we can make and what changes are without, don't come within the Local Authority's remit. So I think that is definitely something we need to work on.

CHAIR: Clearer communication between the Council and the rest of the borough, that could happen I think we need to think about...

NEW SPEAKER: Sue. It is the things we can do to improve it.

CHAIR: We are going to have to think carefully about what the

recommendation needs to be about how to have better communication. Jane, you have a question. JANE: As well as being a commissioner on this commission, I'm also a lay member for the commissioners of the health care in Hammersmith and Fulham. I'm quite concerned to hear that at all these boards you have relating to health issues you don't feel you are being heard because I can tell you locally in Hammersmith and Fulham, people with learning disabilities are a priority for us. So actually, I'm quite concerned to hear what you have had to say. So, I wouldn't mind a bit more evidence so I can follow it up.

CHAIR: How would it be if you set out some of the questions you would like to ask and we can send them to...

JANE: I would probably start off with Faisal and Martin and John, one of you said you don't think you are being heard, because as commissioners we would like to think we give reasons to people, so something is not right. Something is not right. So, I think we need to follow it up.

CHAIR: Okay. So Jane will probably come up with some dynamite questions and we will send them to you. We will follow it up. One more question for Safety Net People First before we move on to the next item, or have a little break.

NEW SPEAKER: Ali said can we have a break...

CHAIR: Martin will still be here.

MARTIN: I will still be here.

CHAIR: Let's have a 5 minute break now.

[SHORT BREAK]

CHAIR: We are going to finish at 7 if it is the last thing I do! Ali has had to leave.

VICTORIA: I was wondering how user friendly, how accessible you find the Council website?

MARTIN: That is a very good question actually. We haven't actually, we don't actually or haven't been on the council website as yet, so we don't know how user friendly it is, but from my own point of view, I think it is user friendly. Really easy to follow, so yes, but when I go back to Safety Net we will be going on to the council website and having a look to see how accessible it really is.

CHAIR: Good question. We are back. Next item is public consultation event. We are going to call them something better than that, I promise you. So a number of us have been meeting, I think we have met three or four times, 3 times, that is me, Tricia, Victoria and Jane, and Peter has been helping whilst Kevin has been unwell, and we thought it would be quite useful to tell you where we have got to in terms of the meeting, the event planning. I think it has been very productive few meetings and I think Tricia, you are going to tell everyone what we have been up to. Also give some details about dates. Things like that. I think it is a double act.

PATRICIA: I will start and you can finish: So, the first event is on Saturday 29 April at Saint Paul's in Hammersmith Broadway from 2 to 4.15 pm, but the venue is booked until 5, but we will meet up at 1. The second, the second meeting event will be on Wednesday 24 May, at the White City Community Centre, but the dates to be confirmed and that is an evening event that 6.30 to 9 pm. It is a Saturday event. So far we have booked the centre, Steve Cowam is available and Hamara Khan is the enquiry person and the centre is available Wednesday evenings till May. The logistics - the rooms at Saint Paul's church has been booked, they have very odd names. It is 2 adjoining rooms. There is enough for 60 people to attend. The cancellation of the second room is without charge up to 28 days before booking. 28 days before the event. The 2 rooms I think will be needed unless we have fewer than thirty people and because there will also be at least 10 others including commissioners, BSL interpreters, Palantypists and general assistants. We will lay out tables in cabaret style. There is accessible toilet right next to the room that we are using and is spacious, although there is no holds. Signs will be helpful as the toilets are not signed at all, but we are going to have labels on them. There is one lift which is big enough for the biggest scooters and wheelchairs though only one in a time in addition to people standing. It is also usable in a fire. And AV support, a Saint Paul's employee will be able to help on the day at no extra charge, and Peter met him. Can't remember his name. We will have microphones, 2 wireless and one wired and signs can be provided. The wifi is free, thank God! And the whole booking will be 758, including VAT. Quotes for tea,

coffee, biscuits, cake, fruit juice and water, came back at 5.70 per person, including VAT plus 54 for staff. We can't take our own food in unfortunately. We have asked...

NEW SPEAKER: Does that 750 include that breakdown you talked about?

CHAIR: That is just the space.

PATRICIA: There is a registration desk, we are going to print labels and we need to get availability of the graphic facilitator, Steven Hodgkins, and Peter won't be there on the day, so I am to be the person to go to for the logistics on the day, it will be fine. The people on the Saturday event, Saturday 29 April, there is a male PA available, we need to find a female PA. Tara needs to check council staff availability.

CHAIR: Which I'm in the process of doing.

PATRICIA: Commissioners to do registration, facilitate and take notes for both exercises. Tara to facilitate feedback with graphic artist and the troubleshooter for that day is me, with briefing from Peter beforehand because he want be there on the day. People at the Wednesday 24 May event is as above, and we need to check with Steve if he can be there and get an inspiring person. The budget.

CHAIR: Don't worry about the budget.

PATRICIA: We have done the publicity, we have done an exciting pamphlet.

CHAIR: Peter has a copy for everyone.

PATRICIA: The publicity, a reminder has been sent out.

CHAIR: Do you remember when we met we decided that we didn't want to confuse the survey coming to an end with the poster for the event, so the poster for the event is probably going to go out tomorrow, latest Monday.

PATRICIA: That was the next thing I was going to say. We are going to send the flyers out, contacts after accessible versions of the survey has been circulated and we need to qualify Kevin's email.

CHAIR: That is less of a problem now because Kevin is slowly back to work, so people that are booking to come along.

PATRICIA: The workshop on the day of the event, that needs to be decided after the survey results, because we can't until we know what the results of the survey is we don't know. So, the timetable for the

Saturday 29 April is 1pm commissioners and other people to arrive, Tara to give briefing. Possible group hug...

CHAIR: Possible group hug!

PATRICIA: No.

CHAIR: All British and Irish.

PATRICIA: Registration, 1.30 registration, 2 pm welcome from Tara to Steve, Tara setting the scene, Steve's vision of DPC and the outcome ahead and. 2.20, result of survey, Kate and Kevin to lead with Ramona as back up...

CHAIR: I haven't talked to Ramona about that yet. You are revealing these jobs we have given people.

PATRICIA: 2.35, inspiring person with practical examples of co-production. 2.45 exercise needs to be confirmed and Tara to get feedback from tables. 3pm, break. 3.15 exercise 2, focus on issues for piloting co-production, have a table for each issue and who wants to be involved and how people want be involved. 3.40, open discussion. 4:00 o'clock round up, person doing the drawings to give feedback or each table to give feedback, we haven't decided, and what's next and 4.15 closed and we have the venue until 5 PM. That allows for people to leave.

CHAIR: I think that's it.

VICTORIA: Very comprehensive.

CHAIR: Shall I say a bit of context around what we want to try and achieve? I guess this is our sixth meeting as commissioners and the survey has gone out, we will say more about it after this, but I think we have all agreed right from the beginning that we also want to find a way for local disabled people to come along to events and talk to us directly about what it is we are wanting to do and how people, what people think are the issues and how people want to be involved and the best way to do it is to organise open public events, so we talked about being careful about how we talk about co production, because it is a word that I think people will struggle with. I think some of us probably do, so I'm going to talk about very briefly at the beginning but then we will talk about working together and partnership working, so that people really understand that we are trying to make change happen in terms of decision-making and

policy setting at the council, rather than trying to understand the complexity of co-production as a word. So I think the important thing for commissioners is we want as many of you to be at the event and being part of the different sections, the different parts of the day or the 2 hours. So for example, Kate and Kevin are going to lead on the survey, because by 29 April hopefully we will have some idea about what the survey is telling us. But also people, commissioners welcoming disabled people coming into the event, facilitating the table discussions, generally running the day. I think we are going to call the day: Nothing about us without us. People have heard that expression before, it is a really well-known expression in disabled person-led organisations, but it really means that everything that happens about disabled people is involving disabled people and led by disabled people, so it is really important on that day that we are seen to be doing that. I haven't spoken to Fawad or Peter about that day but I hope either or both of you are able to join us for that day, I know Natasha has sent the invite out to counsellors, I know you can't make it Sue. I hope you may be able to make the May date.

NEW SPEAKER: Sue. I think it is because it is a Bank Holiday weekend but I'm hoping, I may be going away but my daughter is coming back home from Australia so I am not sure of the plan but I will definitely try and be there. I know that other Chancellors will try and be there, I doubt if Fawad can be there, but the next one hopefully I will definitely get...

CHAIR: It is really important for local disabled people to see that this is not just us lot talking about what we hope will happen. But there is a commitment from the leadership within the Council.

NEW SPEAKER: Sue. Meeting individual. As well as anything else, so I completely understand.

CHAIR: It will also help us write the report. So...

MARTIN: Tara, on 29 April I am afraid I won't be able to make it because I am with my drama company in Stratford on that day.

CHAIR: I'm hoping other Safety Net people will be able to.

MARTIN: What I will do is I will take a few of these to them and I will give them out.

CHAIR: The reason why, because one event is a Saturday for people where Saturdays work, for people that work and also in the evening on

the Wednesday, because daytime and evening works for different people.

MARTIN: That one on the Wednesday I should possibly be able to make. If I can't make it I will try and drag myself.

CHAIR: We have another commission meeting before 29th so we can do some final planning at the next meeting.

NEW SPEAKER: Kate. Are we going to have visual to identify us on the day as commissioners?

CHAIR: Other than badges? There will be badges for sure, but they will be just sticky labels.

RAMONA: Can I say something. If you want people to come to this event, you have to wear a colour that they will be able to distinguish us as the commission and you also, so that we are not blending in with crowd. So if they need to come and find us for any reason, they know who we are. No yellow and no white.

CHAIR: I would never wear either of those colours. That is marvelous for me.

MARTIN: I would.

CHAIR: We have a meeting, I think next week so that is a really good point in terms of, I don't think we can stretch to buying kind of like DPC tee shirts, or anything, but if we all coordinate in terms of the colour that we can all wear.

MARTIN: Blue.

CHAIR: But we need to think about dark or light. But we will think about it.

MARTIN: What about green?

NEW SPEAKER: Sue. What about red?

MARTIN: Purple?

CHAIR: Black. Black please.

MARTIN: Not unless you want us all to run into each other.

CHAIR: Give some thought to it and based on what the planning group thinks in terms of colours that suit us best. But I think bright colours.

RAMONA: No black.

CHAIR: Maybe when we come to at least one or two choices check with you if they work and then everyone can work out what colour we are

going to go for and then find something in our wardrobe.

MARTIN: What about tie dye.

CHAIR: If they haven't got it they have to find something or make it. We will go for a colour. Then Peter was checking if Steven Hodgkins can make 29th, this is a great disabled guy that a number of us has worked with before. He drew what we talked about at the international day of disabled people event in December and I think for us as commissioners it would be a really nice visual of what people talk about on the day. I think it is a really nice - he will then of course describe what he has drawn across those 2 hours but more detail about that nearer the time. But that is it for the day, and really hope as many of you as possible can make 29th and if you can't, 24 May is almost certainly the date. Peter, is it? Are we definite on the date.

NEW SPEAKER: Peter. Booked the space, but I haven't been to see it, so I want to double check but I think it should be good.

CHAIR: Peter is our fantastic logistics person.

RAMONA: The space you booked at Saint Paul's is it upstairs or down stairs?

CHAIR: In the basement.

RAMONA: Oh...

CHAIR: I have not been there.

NEW SPEAKER: Sue. There is a lift.

CHAIR: There is a lift, AoD have used it a number of times. Tricia and Peter have been for a visit.

PATRICIA: There are stairs up.

CHAIR: Kevin has been there before.

VICTORIA: How many commissioners are coming?

RAMONA: I will put it in my diary now.

CHAIR: Ali can make it, Kate can make it, I can't remember, Jane, can you make the 29th?

JANE: YES.

CHAIR: So a good chunk of us, I know it is a Bank Holiday weekend but it was starting to push into May and June which starts to feel a little late, because if you remember back in the first or second meeting we were

keen to get the public events done quite quickly and then we decided it was better to wait and see if the weather gets a bit better. David, I'm going, how are you fixed for 29 April?

NEW SPEAKER: David: I think I am okay. But I will confirm it.

CHAIR: I will move on. The next couple of items are short. Update on surveys, everyone knows that the survey details has gone out, they are up on the website. The Safety Net People First have done a fantastic job in creating an easy read version, I am getting that now from the website, which is fantastic so at the moment the official closing date for it is 20 March, but we are extending it to end of March.

NEW SPEAKER: Peter. It has been extended, that is for the residents.

NEW SPEAKER: Kate: I saw it has had been advertised again in the council email.

CHAIR: I think as at today before 60 odd responses.

NEW SPEAKER: Peter. I think 83 responses from staff, 67 from residents. It is local residents only, but it is a good staff return but hopefully with the wide circulation, hopefully we will get more.

CHAIR: I have a pile of completed hard copies, which is brilliant. Should I give them straight to Kevin? What is best?

NEW SPEAKER: Peter. What are they for?

CHAIR: They are residents surveys completed by some Safety Net People First.

NEW SPEAKER: Peter. Yes...

CHAIR: We will sort it out. Has everyone around the table completed the survey? (no). Neither have I, I will do it this weekend.

JANE: Victoria, do you know if Action on Disability have been included in the survey.

VICTORIA: I think it is on the website and - AoD sent an email out early on after it was published and it has been on the website... .

JANE: I was wondering if Action on Disability were asking everybody who comes to the office to complete the survey.

VICTORIA: I did ask them to do that. I even put it on the notice board and put it in information to all staff.

CHAIR: I think we will get it to DeafPLUS tomorrow.

NEW SPEAKER: Peter: It is actually 2 weeks away now, so if we extend any further it wouldn't be reported till April.

CHAIR: Anything we can do and people like me and David, we will get on and do it and Ramona.

NEW SPEAKER: Peter: There is a large print version on the website as well.

CHAIR: Do everything you can to encourage all disabled people that you know.

RAMONA: I have circulated it.

MARTIN: I have got somewhere in my work place, I am going to give it to some of my disabled people.

CHAIR: That would be great. It is really important, it will be much more powerful in the final report if we can say X hundred, hundreds of disabled people have said this... It will make our job much easier.

CHAIR: I think I will ask Ben Coleman. I don't know why I don't know this, maybe I do know it, he is the cabinet member for 'resident satisfaction' but also community engagement he was saying to me. I will send him a direct email saying can you send it out to all of his contacts. I think the more we can get it at there the better. All right, I think that is all I have to say on the survey. Number 6 is any other business. I have in brackets here 6 month review, because I was hoping there might be a bit of time, but I don't think there is, to get a sense from all of us about how we think things are going. I think what I might do if people can bear it is ring everyone up. Have a chat on the phone.

NEW SPEAKER: Jane. You can send me an email.

VICTORIA: Writing reports, how is it done in practice?

CHAIR: Could we have that as a discussion at either April or may, because I think it will be very difficult to write it as a whole commission. I don't know if anyone has written documents as a big group before, it is just about impossible, so it might well be that like with the public event planning, a smaller group of people get the process started, and that we start to circulate different drafts, but let's have it on the agenda either for April or May because we still have a bit of time. Also I want to check with people if, how people are feeling about the monthly meetings, is it too much for people? But I will do that conversation on the phone

individually then we can have a bit of discussion about that at the next meeting, because in April and May, we have got quite a lot of meetings. We have 2 of these meetings plus the 2 public events and that might feel quite a lot for people. I will speak to individuals on the phone.

MARTIN: You might not be able to get in contact with me because my phone is not working as of now. So when I get a new phone I will email you my new phone number.

CHAIR: As it is almost 7:00 o'clock, can we have the tackling social isolation and loneliness as an agenda item for the next meeting? Has any one got anything else they want to raise at this meeting?

NEW SPEAKER: Peter. One minor thing. Those who weren't at the awards, not awards, the welcome for all commissioners that was held beginning February, and Tricia and Ramona and Victoria were all there, David already had one of these, he picked up one last time but I have these. If anyone wasn't there and would like one of the plaques that was awarded to all commissioners, then I have them here. If you want one. And Jane. If anyone wants one.

CHAIR: Would you like one? Those that have got them already, are they on your wall? David?

NEW SPEAKER: David. I am a bit disappointed that it doesn't have my face on it!

MARTIN: So we can throw darts at it.

CHAIR: It needs to be a recommendation in the final report. All right if that is it, we will draw to a close. And it is 5 seconds to 7. Good work! .
