

Dawes Road Hub
Wednesday 01 February 2017

CHAIR: Welcome. Did everyone have a good new year?

MARTIN: - I lost my grandad.

CHAIR: Sorry to hear that. We are a bit tight, has everyone got enough room? We have got some new faces round the table, people that are coming to present today so it makes sense if we go round and say who we are. I will start with me, Tara Flood, chair of disabled people's commission and go.

>> Patricia Quigley, one of the commissioners.

>> Anna, Heads Up project worker at Mind. User involvement.

>> Adrian Whyatt, representing Heads Up in the consortium.

>> My name is Martin, I'm one of the commissioners and also a chairman of Safety Net People First.

>> Hannah, Martin's PA for the evening.

>> Victoria Brignell, Chair of Action on Disability.

>> Vivienne Lukey, Cabinet Member for Health and Adult Social Care.

>> Kate Betteridge.

>> Henrietta Doyle, Inclusion London.

>> Mike Gannon, a commissioner.

>> David Isaac

NEW SPEAKER: A call from a lady called Ramona. She is running late.

>> Peter Smith, head of policy and strategy H and F.

>> Fawad Bhatti. Apologies Jane Wilmot and one other.

CHAIR: Kevin isn't well, terrible chest infection. Sorry he can't make it. But we have had a good chat so I feel at least I know what has happened over the last few weeks. He wishes us well.

NEW SPEAKER: David. Is this the same thing that continued that he had in January?

CHAIR: He has sent emails over the last few days so we are all up to speed. Do the minutes first. This is our fifth meeting. Has

anyone spotted errors? Across 17 pages. I didn't spot any. Everyone happy? Actions from last meeting but anything that happened as a result of the actions from previous meeting. Item 1.8. Waste and street cleansing report. You remember an email back in May about how individuals might feed in to the work they are doing. Waiting for a reply, so it maybe a reply comes after tonight and he can forward that to people who were interested in it. 1.10, Kevin and Safety Net People First, asked me to pass on to Martin and Hannah that once surveys have been agreed, he will send it to SNPF so that you can do what you need to do. In terms of the minutes, we talked at the last meeting about putting minutes from our meetings up on to the website. Kevin emailed round after that to ask whether or not anyone wanted anything that they said recorded in previous minutes either removed or anonymised. I understand that we heard from everyone now. So unless someone has got something they thought about since and if you have please let Kevin no, but if he hasn't heard they will go up on website. A lot of people will see what we have talked about. 1.11 Head of Insight, Kevin has asked to have it recorded that he has had fantastic help from Milan and Kirsty in that department and I think he said something like the surveys wouldn't have got to the state they got to without their help so it is important to minute thanks to them. First action middle of page 4, Peter to circulate meeting dates which has happened. Top of page 5, action: Draft strategy of tackling social isolation and loneliness to be brought to next meeting. I know that there has been a conversation between Fawad and Kevin.

NEW SPEAKER: Fawad. Strategy has been developed from a workshop with local community sector so group officers have developed strategy to make sure that what the community voluntary sector said at the workshop and good practice elsewhere campaigns loneliness supported by lot of different organisations. We are at the stage where the high level strategy is more or less done and ready for open consultation. So the 17 February to 10 March will be an open consultation and we can also - I say we, colleagues from public health are very happy to come and present at the next meeting, so different avenues and we are also going to

organise a follow-up workshop.

(Ramona arrives).

On 28th, Action on Disability attended the first workshop so there is a few avenues there. So we can come here, get public health to present to the Commission.

NEW SPEAKER: Peter. To clarify, I met with Anna this morning to discuss and she said she would release an up to date draft on 17 February. It is probably not ideal because it is still being developed but she said it will be ready by 17 February and after 3 week period of consultation to 10 March and come on 12 March with a revised version or feeding back your comments.

CHAIR: Consultation will be launched 17 February. Paper will be circulated to commissioners then for individuals to respond and then we can speak about whether or not it would be useful to have someone present to us.

NEW SPEAKER: Fawad. There is workshop as well if any commissioners are interested.

NEW SPEAKER: Victoria. The Joe Cox foundation is spearheading a drive to combat loneliness.

CHAIR: I think it was on the news yesterday. It would be useful to follow up about the consultation being open, the workshop date and how people can get themselves registered for the workshop. Page 9, bottom. Kevin to circulate copy of Tom's presentation to Commission along with copy of executive summary. He assured me that was sent on 4 January. Page 13. Kevin to obtain a copy of new Hounslow compact. I understand he has done that but usefully Ian Lawry is going as part of his presentation to talk about the Hammersmith and Fulham compact, which we thought was more relevant, and the next action on same page, Kamran to forward a web link to Local Voices. That didn't happen but Kevin is picking that up and will circulate something after today. Apologies that it didn't get followed up sooner. Item 4, it is not an action but an update, what will success look like? That change has been made from council manifesto to council corporate plan and the final document in terms of what successful looks like will be circulated. Last meeting we were happy with rest of the text.

Lastly, bottom page 15. Commissioners to submit short biogs to Kevin by 15 January, I was the last person to do it but everyone else has done it. I think 2 people where we don't have photos but Kevin will follow that up. (Martin's photo to come).

NEW SPEAKER: Peter: There are photos from the reception. Chairman with the mayor.

CHAIR: Page 17, commissioners who wish to attend the meeting with DeafPLUS to let Kevin know. Kevin since the last meeting has been trying to get hold of DeafPLUS and Ali has been trying to do that but with no success, so he has emailed again so essentially the meeting hasn't happened. Hopefully there will be something that happens after tonight but if there is, we will let you know between now and the rest of the meeting.

I wondered if Tricia or Ramona or Victoria wanted to say anything about the Mayor's reception that happened on Monday night.

NEW SPEAKER: Victoria: It was a lovely evening, very informal, it was good chance to meet and network with people from other commissions. So also presentation of [inaudible] commissioners which was quite special and I explained who we were and what our aims were and what progress we made and what our timetable was. Patricia and I had a long chat with Steve Cowan after the presentation.

NEW SPEAKER: Patricia: I have the plaque. We had to shake hands with the Mayor and apparently it says - I didn't learn Latin at all, forgive me. Spectrum something or other which basically means -- thank God for Google -- because it means let us be judged by our actions. Our acts.

NEW SPEAKER: Peter. Can I say there is enough plaques for all members of the Commission. The next meeting in the town hall I will provide you with them, those who weren't able to get there, next time.

NEW SPEAKER: Victoria. There will be a photo of the 4 us which will go on the Commission website.

NEW SPEAKER: Peter. There will be on the council website photos from that evening

NEW SPEAKER: Ramona: I love my plaque. It was interesting meeting all the different commissions and seeing how they have come on from when they first set up, not knowing anything about what you were going into.

CHAIR: We definitely need to find a way of staying in contact on a regular basis so we can share learning.

We have 3 presentations. I will go for 2 presentations then a break. First one is Henrietta Doyle, Inclusion London.

Henrietta has the job of giving us a kind of presentation about the item on the agenda which is called the reality for disabled people across London, which is nice and juicy. Speak for 10 or 15 minutes and then questions from us.

HENRIETTA: Inclusion London may not be familiar to everyone round the table, we are a disabled people's pan-London, pan-disability organisation and we provide support to local user-led disabled people's, deaf and disabled people's organisations in London. It might be support for business, we have an 'into sport project' and our newest member of staff is Svetlana Katova who is taking on strategic court cases related to the Equality Act and the Human Rights Act. I won't go through all the services because it would take up my 25 minutes. I thought I would tell you about when Kevin sat down with me and talked to me about what you are doing here, and also obviously what he wanted from me for the presentation, and when I went away and absorbed it I thought: This is really something different, I know there has been pockets but Kevin talked about basing your work on the UN Convention on the Rights of People with Disabilities and that it is based, policy formed from your own experience, disabled people's experiences and that it is co-production, you are equal partners forming the policy, that is, well done for getting here, for championing a new way so well done for getting here and I know about the success on social care low payments and ILF funding ring-fencing till 2018. So you have some successes already under your belt.

I have to say that is the kind of bright and light bit. At the end, towards the end of the presentation I will share with you some pointers for success regarding co-production that Tracey Lazard gave me which I thought would be helpful, based on

her experience in Islington. But now I am going to share with you what is happening to disabled people in London and the UK. Most of the statistics I will give you are UK-wide, but I will give you some of the experiences that I have heard from mainly from people in London. I am the policy officer, so, it is my role to provide responses to enquiries and consultations and also help support disabled people's organisations so I'm going to talk about the range of what is happening to disabled people. There is about 1.2m disabled people in London, and 12.2m disabled people in the UK, and it is about 19 per cent of the population and has been quite steady at that for some years. Disabled people are particularly, well the 48 per cent of disabled people, or households with disabled people live in poverty. Disabled people have higher risk of poverty and probably by the end of my presentation you will be understanding why if you don't already know. The big issue is welfare reform, Welfare Reform Act 2012 and Welfare and Employment Act. There has been a number of issues that came out of that and maybe telling you what you already know and you know from experience but it is just to give you a broad overview. One of the issues that disabled people find very difficult is the work capability assessment and the personal independence assessment. The assessments became, or eligibility criteria was narrowed and I think the main complaint that comes through to me and other disabled people's organisations is the huge frustration, because they are so inaccurate. They don't bear any resemblance, the report that the assessor and the decision-maker give doesn't bear any resemblance to the information the disabled person has given in the assessment, put on their form or the GPs or whatever medical professional has given. Again and again that evidence is ignored. Actually the National Audit Office said that only 13 per cent of PIP assessments and work capability assessments reached the required standard, so that means 87 per cent are below standard. So it is known from the statistics that they are not accurate and what is another hurdle is that people now can't go direct to appeal, they have to go through a

process called mandatory reconsideration and the majority of people that go to mandatory reconsideration the decision isn't changed and a lot of people drop out at that point, they don't then go on to appeal, even though 58 per cent of appeals are successful. So those inaccurate assessments leave people without the benefit that they are entitled to and with the PIP assessment, there has been a change of eligibility criteria, so many people are losing Motability vehicles. I have a figure here, it is 700 a week of people across the UK. Before PIP people weren't losing them, it is because this is to do with PIP and they narrowed the eligibility criteria, changed the amount that you walk - I think 50 metres and they changed it, so 350,000 vehicles returned in 2016. That leaves people marooned at home. A lot of areas transport isn't accessible.

NEW SPEAKER: Martin. Thank God I'm able to get out.

HENRIETTA: There is another area which is the social housing side criteria, commonly known as the bedroom tax which causes difficulties often because there isn't accessible accommodation to move in. Someone might have 2 or 3 bedrooms and another one a one bedroom available which means they have their rent reduced 14 pounds a week for one bedroom. There has been a recent court case where a person, a disabled person could not sleep in the same room and also at the same time disabled child - anyway, I will stick with the person who couldn't sleep in the same room - they won their case. I wasn't going to go into detail but there has been a win.

The other issue I wanted to talk about is sanctions which are having a massive impact on those that they are applied to. I will give you one case example that came to me in November, quite a recent one, of an autistic young man and he was on job seekers allowance looking for work, he really wanted work and he was given one benefit sanction and then the second, he had a second one because he couldn't fill in the forms, because of his learning difficulties. So there is a court case that could be there, because the reasonable adjustments were not being made. And that sanction had a devastating impact for his mental health and at last it has been recognised by the

NAO that sanctions don't work they said in a report that for people, disabled people who receive sanctions of their employment support allowance actually pushes people away and on JSA, which was for everyone, there wasn't any indication really that they were successful and from the cases I have had over and over again, the impact on someone's health grown to the point of eviction or sometimes eviction, forced to use food banks, it is an incredibly destructive policy. One thing I thought that might be useful from your data collection point of view, 3 freedom of information requests what was revealed was that it is people with mental health support needs and learning disabilities that receive the most sanctions and I feel that that is a campaign tool because sanctions are given for someone missing an appointment or not filling in a form, really reasonable adjustments good be made because it is not right that someone with a mental health support need is penalised. Sanctions are being handed out when someone has been 5 minutes late or 15 minutes late for an appointment or haven't received the appointment letter and still kept sanctions. The Mike Leigh film didn't exaggerate.

NEW SPEAKER: Ken Loach.

HENRIETTA.

1,749 employment support sanctions in June. The highest was in 2014, 2,695.

NEW SPEAKER: Patricia: Was that just for London.

HENRIETTA: The whole country, most of the statistics are difficult to do with employment. Most of the statistics I will give out are UK. A lot of the benefits don't break down by that detail in regions. Still sticking with disabled people's experience, this is UK-wide, social care and support packages are being cut hugely. Why? Because 4.6m, sorry, billion, have been cut from the amount of money that councils get for social care over 5 years. So there has been massive cuts and that is impacting and we call it a clean feed model of social care where it is absolutely basic, it is care to get up, get dressed, eat and basically go back to bed again. So any involvement and participation in the community which is central to Art.19 independent living, is just wiped out of the window. That is

why what you have achieved here with social care is such a massive win.

ILF funding as you know has been devolved. My colleague Ellen Clifford did a survey, I think it was a London survey and what came out of that survey was that it is very much a postcode lottery. Some disabled people like residents in Hammersmith, their care packages under the ILF, the funding has remained the same. In other areas it has been drastically cut, so it varies very much from borough to borough.

Employment, sorry I am afraid it is a story of doom right through - Access to Work which was called at one time one of the best kept secrets, it still is a good scheme but what disabled people that have got it are experiencing is that their funding has been cut and one of the issues is with deaf people that they have had a review, they have not been informed they are having a review, their funding has been cut, but they haven't been informed it was cut, so they have employed BSL interpreters that they need as normal part of their work and then found they haven't got the funding so they are then out of pocket or their BSL interpreter isn't being paid but it is not only deaf people that are experiencing cuts. Other disabled people are having reviews and their packages being cut.

NEW SPEAKER: Victoria. The government is imposing caps on how much you can claim. It probably affects deaf people because of BSL interpreters.

HENRIETTA: I think it happened to a diplomat. 2 more minutes.

NEW SPEAKER: Martin: It is just getting interesting.

HENRIETTA: I think I have given you a flavour of what happened.

NEW SPEAKER: Martin: I'm still waiting for the chocolate part to come.

HENRIETTA: The presentation will be circulated after so the bit you may have missed or I haven't had time to cover you won't lose out on. This is based on Tracey Lazard, the CEO of Inclusion London experience in Islington, 6 years, and here is what she thinks are the key elements for success. She talked about crucial leadership buy in from the top. In Islington the deputy director chaired the meeting and the director of whatever policy that was

under discussion attended the meeting. I shouldn't talk to that half... and agreed a process for co-producing and scrutinising the policy through quarterly strategic meetings and out of that came an agreed action plan. They focused on a different policy at each quarterly meeting and they had a reparation meeting to identify key issues that were put into writing and sent to the director. The director then responded and this is before the meeting and then at the meeting they then discussed the difference between and came to an agreement. And an action plan after each meeting. Islington looked at current policy and raised needs and issues. Out of that developed new policies, some of their wins were that the finance department started to produce council tax information in easy read and plain English and the housing department agreed to give a visual warning for door bells for deaf residents. Really important, but I think you have it here anyway: Adequate support for all meetings, so BSL, Palantypist, so I think that is already in place. That's it. In case it is useful for you to know, independent living in Scotland has produced a toolkit and in my presentation there is a link to it. A co-production toolkit. I can't speak whether it will be useful to you or not but you could have a look at it. Questions. That was a whistlestop tour.

NEW SPEAKER: Patricia: The benefits ESA & PIP and I'm sure along with many others they are done on a point system, so where you might, as a disabled person, where you might score low on a section, you know you are asked a particular question and then you might have three or four different sub answers to give, so on one of them you might score low and then in another one you might score high. So I think the problem is that actually it is the scoring system that is the problem, because they don't seem to be understanding the needs of disabled people, because what they might score low on one but you know what I'm trying to say. It is a numbers system. They are not, they don't see the person and I'm not saying that for every form that is put in someone has to sit there and read the forms but it is a numbers system, so if you go over 50 points the entry level 50 points to get the benefit, but you go over by 5, then you are just put to one side.

HENRIETTA: I think there is 2 issues. We probably could have a

big discussion about the assessments and how they need to be reformed. I totally agree, they don't see the person. I have gone slightly blank, firstly they need to be based on social model of disability. They don't recognise, say for the employment support allowance, the barriers that disabled people face regarding employment, taking into consideration physical barriers or the attitudes of employers. You have to remember this, these changes, this welfare reform and the tightening came because the government wanted to reduce the number of people on benefits. That is basically the driver. If I wasn't doing the work I do and receiving emails from disabled people I wouldn't believe how inaccurate they were and it wouldn't make sense unless you knew that the government wants to reduce the amount of money and for instance 2 cases come to mind where a disabled person had a home visit, she was assessed in bed but she had to get up and take the few steps to go to the loo. She was then assessed as being fully mobile so there is an agenda behind it.

NEW SPEAKER: Patricia. The reason I'm kind of going down this line is I had a couple of years ago to fill in an ESA form and I looked at the questions and I filled it in quite honestly and somebody then came along and I handed it and said to them can you check this over for me and they checked it over and I had completely answered the wrong, the questions the wrong way because I was asked could I do such a thing. Quite honestly I answered it, yes I can. The question was could you do it 20 or 30 times.

NEW SPEAKER: Henrietta: That is supposed to be part of the assessment.

NEW SPEAKER: I had read the whole of the ESA forms completely wrong. I viewed it that I was asked could I do this, yes I can do that. Can you do it 20 or 30 times?

NEW SPEAKER: Ramona: Last year when they were starting to introduce PIP the person who was for DWP for West London, Colin Morris, I met him because he did a talk at Action on Disability and it was quite interesting how he said the points system was scored, so I do have information of how it is scored and how you will be scored and what the questions they ask you is but he said half the

people that do these assessments when you go are not qualified. They use paramedics they take off the road. The only time someone is qualified to do the assessment properly is when you go to the appeal. Also the second thing is when you do the form, when you go to the assessment they also encourage that you get advocacy people to fill in your form and make sure you take someone with you because as a disabled person you will say yes, yes to everything and you can't do it.

HENRIETTA: One of the DPPOs in London always if they can send someone to take notes, so there is a written record of what is said so they have proof.

NEW SPEAKER: Ramona. But say they have like a ball or they have 20p and drop it on the floor and say can you see where that dropped.

NEW SPEAKER: Henrietta: I am sure visually impaired people may have something from their consultant saying what they can see. As I said, 87 per cent based are below standard from the NAO. I have got the evidence I'm given by disabled people through emails, so it is not only my opinion, it has been officially acknowledged.

NEW SPEAKER: Kate. Not to do with benefits but I wondered from the things you told us if there is anything particular about London that makes the experience different for us.

NEW SPEAKER: Henrietta: What immediately comes to mind is 2 things: Housing, because housing costs have risen so much in London, further than anywhere in the country, so the lack of accessible housing. There is also the Mayor's crime and policing draft plan is out for consultation and is looking and the higher numbers of people with mental health support needs in London and the numbers of people with mental health needs are rising and I could look to the pressures of all that I have been describing as causing huge amount of distress.

CHAIR: That was fantastic. Are we able to send burning questions to you?

NEW SPEAKER: Henrietta. I am here to give you any supporting information that is useful.

NEW SPEAKER: Adrian. The figures for number of disabled people

were far too low. Back in 2005, the then opposition education spokesperson, one David Cameron, asked a very good question which was how come in the independent sector 22 per cent have been diagnosed as dyslexic. Lack of funding and awareness et cetera. But if you take that one stat that is more than your: And we need...

CHAIR: We are going to have to stop.

NEW SPEAKER: Henrietta: I had slide about that.

CHAIR: I am very keen but I will follow up with you how you think we -- is there any potential for this to feed into anything the Mayor of London is doing in terms of advising the London plan but? I will save that. Thank you for your time. We are going to seamlessly move across to Adrian.

NEW SPEAKER: Adrian. Can I introduce heads up.

NEW SPEAKER: Heads up is a Hammersmith and Fulham project. It is co-production. We have a network of thousand service users who attend activities for involvement and co-production. Some are involvement, primary care, mental health service forums and secondary care and mental health forums where the service user will come and bring feedback about the service they are using, suggesting what to improve it and then pass it on to the relevant people. We do co-production as well, we have a Heads Up committee. They are a group of 10 service users who meet once a month and we discuss, plan, share ideas about how to improve things and hold the trust to account to make sure they are doing co-production and that is improving as much as they can. We offer to place service users on interview panels so they have a say on who gets to work with health difficulties, we place service users on meetings, we recently placed 2 service users at the Hammersmith and Fulham mental health IT partnership board for the adult social care strategy. We also provide training to our members so that is a general idea of heads up and I will hand over to Adrian.

NEW SPEAKER: Adrian. Well, some good news and some, about 4 successes that we readily identify. One was the setting up of the Hawley(?) support group and I was there at the meeting that commissioned that as secretary of the peer support group, a user-led entirely self-funded organisation that meets at the London

action resource centre at Whitechapel since 2012. As a consequence of that and with the support of the fire brigade as well, who are keen on this area, that has been funded, and continues to meet as a peer support group and helps quite a number of people. Another thing Heads Up has enabled people to participate in research and treatment initiative which otherwise they might not be able to take part in because the big centres for a lot of research tend to be based at south London and Maudsley trust, not local, and places, Guy's Hospital, spread all over. And also, the recovery college at West London mental health trust, which I am a peer trainer there and there are a number of service users who are peer trainers. It was as far as I am aware the first recovery college to do a course on acquired brain injury, I helped to co-deliver that, and it is also delivering on things ranging from autism to getting benefits and dealing with the system. Also for some conditions like for example personality disorder they do have quite a long social interaction training programme which is free to access. A lot of people can't get any other form of treatment. However there are areas where user involvement and co-production should improve. There is no consistency and no genuine involvement in regional and national services really outside of the things done by West London mental health trust. There needs to be and these again that I mentioned all over. So for example, you have institute of psychiatry Kings College London, that people seek services for, south London and Maudsley trust, brain injury and many specialist services, Guy's and Saint Thomas's hospital trust for dyslexia and St George's Hospital for brain injury and rehab, if you can manage to get it, which is difficult. Then some of these things are even outside the Greater London area, such as the discovery centre for dyspraxia which is in Cardiff, not even in England, but that is the main centre and that is set up by someone who has dyspraxia herself, was a GP and then specialised as a professor in the area. Called Dr. Amanda Kervy(?). Also another thing that is worth noting is that West London mental health trust is responsible for Broadmoor. When we went there for an involvement day there was no involvement of the inpatients at the event. That does affect some

people here and there are also things like forensic services that inpatients in general, there is a real problem with involvement and that could be improved in part by having meetings. A lot can't come out, having them where they are. In Hammersmith and Fulham, there is nothing much significant around brain injury in contrast to Westminster, for example, which have comprehensive services by linking up with 12 east London Boroughs to fund Headway House east London, which even includes a writer in residence. Here it is a desert and there they have everything. Kensington and Chelsea there is a pilot project, Hammersmith and Fulham and the local clinical commissioning group have failed to commission any specific services for longterm survivors of brain injury and also don't have anyone with any expertise in the area. I know that from having met with them to discuss local services despite recommendations that this area and areas of high functioning autism and learning difficulties were particularly bad, nothing has been commissioned. This compares unfavourably with other local authority area. So we have Newham, specially the case of high functioning autism, including Aspergers syndrome which is a 24/7 service so people can run in in the night if they are anxious, and they have done that for years and it cost them less money. Also in Buckinghamshire they have a comprehensive brain injury service which is best practice. There are other areas like Cardiff where they have very good provision for specific learning difficulties. There is a problem with the lack of any funding for user-led organisations in this area. It is a fact that many of these organisations apply for funding but if you take for example the Autism Act, autistic people didn't want it, there has yet to be a single so much as part-time post funded at any user-led organisation. They have applied for much funding but got nothing. Other than stroke survivors, or survivors of acquired brain injury, the only organisation is SAB which is user-led, based in California, not exactly local. So it is a real problem with capacity building here. I think there is an attitudinal problem with funders including voluntary sectors refusing to fund these organisations when they apply for funding. Always give some excuse. And looking at that there are problems trying to bring test cases and the problems

even with the EU whom I shopped to the UN in 2009 for their nasty bright lights, so-called eco friendly lights, Directive which there is a lot of complaints about because they could have done it in a way which doesn't impact on people. So in the review of this, this isn't mentioned, even though the UN published my report on it. And so we also need to consider that in the words of the late Dave Morris, 95 per cent of people prefer something other than black type on a white background. Sensory audits are not being done, this room is terrible by the way. It was much better in Victorian times, as has been recognised by a couple of politicians, most recently Michael Portillo and John Macdonald. So we need to be considering that sensory things and having things that have...

NEW SPEAKER: Ramona. That is very broad.

NEW SPEAKER: Adrian. Not bright white background but more mellow. They did understand this in Victorian times. Good examples of some of the museums, John Snow museum.

CHAIR: Can we come on to questions. Can I start by saying you talked about co-production at the beginning. Is there a policy that you could share with us that sets out the commitment to co-production that is drafted by Heads Up or is it West London mental health trust, it would be useful to see that.

NEW SPEAKER: They do have a policy, guideline of how to involve patients and service users in everything they do, especially like meetings and interview panels and consultation on various documents and strategies. But I can send that.

NEW SPEAKER: Adrian. They also did seed funding for West London collaborative, which is basically user run and user-led. Of course whether it will be able to sustain itself over the long run ---

NEW SPEAKER: Mike. When you mentioned about this group, is it a focus group.

NEW SPEAKER: The Heads Up Committee is a group of service users who meet up every month and we have an action log, so we have everyone bringing their ideas and their issues to the table and we discuss it and we make an action plan of how to implement changes or how to get to where we want to get to and what issues are there and I go to the inpatient ward and do my forums there with a committee member and that feedback is taken to the

inpatient ward and the comments of the manager I also take to the committee and we discuss that. Together we try and do it.

NEW SPEAKER: Mike. I had a meeting with Jane on 21 January, with David Byrnes, and the question of co-production came up. There seems to be 2 ways of doing it. One is the one that you mentioned, the other was for people to be almost embedded with the teams and that would be more of a direct involvement. But that would seem to be not quite the attitude you are taking.

NEW SPEAKER: In a way it is because then the committee members do take part or sit on various meetings or steering groups outside of the committee like the implementation group for adult social care. I have one ex committee member who is sitting on that board of that meeting and they are part of that process. They have things going on and then they come together and discuss things. Heads Up is more about involvement.

Co-production, we promote it and we do facilitate some but we were saying about West London collaborative, they were founded through the West London mental health trust and do pure co-production and their CEO was an inpatient, so it is user-led completely.

NEW SPEAKER: Adrian. We do 4 brief recommendations that we came up with that could be done quickly. The first one is to hold meeting in all parts of the borough, this is because of difficulties with travel and some people with mental health conditions can't go beyond a very local area. People should be allowed to have a travel companion in terms of transport, they do have that in Wales. By having more local meetings and forums the evidence is it would bring in more people, by local it means not just somewhere in Fulham but Parsons Green, really local. Also looking at peer support groups, creating them around the borough, hubs, looking at natural communities, projects that attract people locally.

Another thing is help people to get online to use technology. A lot of people with mental health issues, over 90 per cent, spend too much when they are going through a crisis then end up quite a lot having no money at all and can't afford a mobile phone or anything like that. Maybe we can have one little test about what they can afford. Become aware of rights, and finally cater to needs of

groups to provide alternative colours of screen and universal design principles.

CHAIR: Thank you. Can I ask Susie: Are you ok with one more question?

NEW SPEAKER: Ramona: You mentioned about sensory impairments and these things. Visually impaired people are, because you don't have your eyes you do can have a mental health illness because you become isolated. But when you were reading those statistics, there was no mention about anything about visual impairment or you mentioned about the lighting, but the lighting and grey background that is a very grey area because many different eyesights, some like yellow on blue, some like white, so it is a very, this room is okay for some visually impaired people, and some would say no. You can't always please everyone.

NEW SPEAKER: Adrian. That is why I mentioned universal design and these area. Following universal design you can create design that works for everyone, or almost everyone.

CHAIR: That is a great point to finish on. Poor Susie has been typing for over an hour.

NEW SPEAKER: Martin. I can see he is keen and eager to go on.

CHAIR: We will have 5 minutes break.

[Short break]

CHAIR: I am going to move swiftly on, I don't know if you know everyone, Ian, but what we will do is go round and say who we are, because you weren't here for the first part of the meeting. Ian Lowry, Chief Executive of SOBUS -- I can't remember what it stand for.

NEW SPEAKER: It isn't an acronym.

NEW SPEAKER: Social business.

CHAIR: It is not a real world. An abbreviation. I'm Tara Flood, I'm the chair, and we will go in this direction. (round table introductions again).

CHAIR: You will talk about new way of working together locally.

NEW SPEAKER: Ian. Yes, so I think you should have seen this

report that went to the policy, health and social care policy and accountability committee in March last year. So I won't go through it in too much detail. A brief background about SOBUS. We provide support to the voluntary sector on Hammersmith and Fulham, it ranges from one-to-one advice for groups, support around premises and meetings like this, we also support them to access funding, and we have been getting a grants programme running, funded by the CCG, which I currently running as well as ...

NEW SPEAKER: Martin. What is the CCG.

NEW SPEAKER: Ian: Hammersmith and Fulham clinical commissioning group, they fund the health services in Hammersmith and Fulham. We work closely with them, with the Council, and now starting to develop our relationship with organisations like the development corporation who are responsible for the regeneration in the north of the borough, we had a meeting with them and we are looking at developing a bid with Action on Disability around some work they are interested in doing around engaging and understanding better the needs of disabled people specifically around employment, which helpfully we will find out whether it has been successful shortly. Work on co-production came out of work we were doing with voluntary and community sector groups and with Councillors and technical officers about the need to look at how services can be redesigned so that they were more effective both in terms of meeting needs of service users but also in terms of cost pressures and other things going on. It has been supported by Councillor Lukey and Macmillan and we set up a working group which was made up of council officers, voluntary sector organisations and local residents, to look at what method and way that we could look at redesigning services so there was a framework to it and so it was person-centered, service user-centered. Not just around how it was designed but also how it was delivered because the thing about co-production if you are doing a co-production it is not just about engaging with people to ask them what they want, it is also about making sure that they are involved in the procurement and delivery process and not seeing service users as passive recipients but as active parties of the process. We started that process and there

are 6 principles within the report, some of those about treating people equally as partners and having something to contribute towards the process, blurring the boundaries between professionals and service users, making sure that it is a reciprocal arrangement and you are looking at it without any real boundaries in terms of where the service might start and finish, whether that is financial boundaries, whether it is geographical boundaries, whatever it might be we piloted or chose to pilot this on 3 areas. One around user services; another was carer support service and then the supported employment service. The carers service is currently out for tender at the moment and the youth partnership work, there was a launch event in November last year that launched the report and that is now publically available and the Council are currently going through their integrated family support service process which builds on some of the recommendations in the partnership report. We have tested it on a number of different areas and that has given us a sort of Charter or a pro forma that gives a bit of a framework to work with, so it is important that when you are looking at a need or an area where residents want to change services, you have a shared vision as to what you are trying to achieve, not all trying to get to the same place, it ends up a bit messy. A really good understanding of who is going to be part of that process and the roles that those people play in that process.

Then what are the objectives? What needs to be achieved throughout that? Then there is things around the governance, what is the purpose and expectation of the group and being up front about it; what are the resources and that has been a massive learning to make sure those are integrated, any decision-making processes and accountability, sometimes when you are bringing a range of partners together that is not always clear, so making sure that is as clear as possible, allowing suitable time for the process. To do something right sometimes takes longer than people expect so it is important to allow the appropriate amount of time rather than saying this is the amount of time we have and therefore it should be done in the timeframe. Thinking about the budgets that are

available and not just necessarily the statutory budgets, thinking about the financial resources that other people may bring into that, whether funders and the voluntary community sector, whether around in kind contribution, thinking about all the resources, financial and non financial available. Making sure you are considering legal requirements because those will need to be met, a range of different things and where there is sign off by different bodies, making sure it is incorporated in to the process. There are a number of lessons learned from the 3 pilots, really important that people that are engaging in this process are trained and have knowledge and experience of it, otherwise you end up doing on the job training, which can slow down the process. Having somebody to facilitate the process has certainly enabled the work to move more quickly and to be able to drive that. Resources to support people to be involved in that process. Sometimes it is financial and sometimes with the Commission it is about the additional resources, like the typist and interpreters and things like that and facilities that enable people to take part, in terms of whether volunteer expenses or payment, and whether it is also not everyone will necessarily come to a meeting especially around the youth work, we ask young people how they want to engage in the process and they said very clearly we don't want to come to a meeting, you can have it in the evening when we could attend, outside of school time but we don't want to. So we convened a youth panel, so the youth partnership developed what it thought was based on the research that the youth Councillor has done and other providers, it developed recommendations and then it put that to the youth panel for them to comment on and to give feedback and amend them basically. That is how we involved young people. It is also around surveys and other things because not everyone will be able to make it to meetings. Also about not necessarily long surveys but sometimes we didn't get into it but looking at quick questions, like on twitter, yes or no answer, but doing that on a regular basis over a period of time, so that you have got that ongoing engagement in the process, rather than saying: Right, fill out

this 50 page questionnaire and send it back to us. Looking at all of that. Talked about the commitment from all partners to the process and the provision, sign off at the stages by all partners where it is needed, and other processes that maybe going on that can impact on that making sure you are aware as much as possible that everything maybe going on in the wider environment.

Now we have got some real life experience in terms of how that works, what has worked for us, not has not work so well, the plan is for the working group to come back together next week in fact, and write a report that will be available for resident's for the council, for the clinical commissioning group for the VCS and for funders, the voluntary community sector and funders because the learning isn't just for, it is not necessarily the voluntary community sector saying we are perfect, this is how everyone else needs to do it, it is about everyone changing and there is learning for everyone in this process. Nobody is ever perfect and nobody ever does everything right so it is about saying this is the learning that we have had, this is how we think that it can be embedded into how needs are met and how services redesigned in the future in Hammersmith and Fulham and this is what we do to respond to that and looking at stages in that, so it is a journey and we can then mark ourselves to say okay, we have done that bit, now we need to be doing more of this and each time for it to be a reflective process, you implement co-production processes on the carers support service it was a co-production, some of it was already in process, so the next not necessarily in the next carers' report service but the next service where we look at co-production, how do we take it the next step further and all way taking the lessons learned from the last process and feeding it into the next process.

That is a whistle stop tour of what we have done over the last 18 months. I have invited Kevin to join the working group so if he is not available we can have someone else on the Commission if that is appropriate. And we want to make sure that our learning is shared with as many people as possible,

which is why we did the PAC paper earlier on, because of changes within staffing of the CCG, we haven't managed to get it through their process at the moment but the idea is that a similar paper to the PAC paper will go to the CCG and we want to then write up more detailed and fuller report.

CHAIR: That was whistle stop, great. Anyone got questions for Ian?

NEW SPEAKER: Adrian: You mentioned project helping people into employment, things like that. Disabled people are more likely to be self-employed than the rest of the population even though we are less likely to be in employment, possibly because that way we can negotiate some of our reasonable adjustments. And so I wondered what it does with things like getting people into self employment as one of the options helping to develop people in that way.

NEW SPEAKER: Ian: One of the pilots was around support employment service which didn't go ahead as a co-production pilot, so in terms of needs of residents, the whole point is that, in terms of co-production is it shouldn't be driven by a specific service needing to be commissioned, it should be starting with okay, what are the needs of our local residents and how do we respond to those needs? What we might find, because we are not starting with a brand new community or brand new UK or brand new Hammersmith and Fulham council, there maybe existing services in place and that is when you say okay, that is what we are doing now, that is what we did in the past, let's start with the needs, what if we were starting afresh what would it look like? That is the holistic, the full co-production where you start with what do we want to do and then you say okay at the moment we are commissioning these new services and we want to decommission those and we want to... but like I said, the world is not as simple as that and we need a transition and move towards doing this in the future.

NEW SPEAKER: Ramona: You were talking about, going back about being self-employed even as a disabled person, getting into work is quite difficult and I have been on many, many different employment programmes. I gave up, because you are disabled

but they might send you to one programme, they don't know about your disability and so what is different about SOBUS?

NEW SPEAKER: Ian. We are not specifically doing anything around employment support for disabled people. We support the voluntary community sector so I mentioned 2 things to do with employment, one around the old development corporation, a long term regeneration scheme covering parts of Hammersmith, Brent and Ealing. We put in a proposal at their request to look at what services are available for disabled people around employment and how they can engage with disabled people in terms of shaping that, that regeneration programme into the future and because we are not specialists in terms of disabled people, we have written that bit and submitted it with Action on Disability who are doing a lot of work around employment and disabled people. So I don't want to, we are not getting in to the field of providing support services for disabled people around employment. So it is very clear as an infrastructure organisation that we support organisations. We don't work with directly with residents and service users. There are some introductory organisations that have drifted into that because of financial reasons and my board of trustees have been clear, we won't compete against the organisations we are here to support. That is where we are doing the work. In terms of the supported employment service that was a council service, that didn't end up happening as a co-production process. There is some learning we can take from it but not as much as with the carers.

CHAIR: Ian, could I ask you, when we met last time Sarah and Kamran were here from Action on Disability. We talked about definitions of co-production and Sarah was talking about compacts. And Kevin when talking about presenting that said it would be helpful for you to share with us what you know about the Hammersmith and Fulham compact.

NEW SPEAKER: Ian. I believe there is a compact. It is not, we don't reference it on a regular basis in terms of the compact, I know in other boroughs there is a almost, I'm trying to think of the right word, almost point by point reference to a compact and where a compact is or isn't met, almost in a very contractual way and from what I have experienced of working with the Councillors and

officers and the thing about co-production is it is about working together mutually and yes holding each other to account but not necessarily to a preset description of how we are going to work. In terms of some of the Charter, this is how we want to work together but then when you are doing different pieces of work it is then saying actually this is what is appropriate for this piece of work, these are the guiding principles but actually what we need in terms of accessibility is different for this piece of work and the other pieces of work. So we don't reference it in the same way.

CHAIR: Is it a live document? What status does it have?

NEW SPEAKER: Ian: I guess it is a live document I don't know how...

CHAIR: Does anyone know?

NEW SPEAKER: Councillor Lukey: I don't think we have looked at it since we came into power. Clearly because there was a point when everyone had to do it because the government said you have to have these compacts, but I imagine under the previous administration when so many things got closed down, it was a waste of time even trying to look at it -- I don't know. Depends what people think. We could revive it but what is the point of having a document if no one actually looks at it.

NEW SPEAKER: Peter: I recall it from the previous administration, it was in reaction to a government initiative to try and get some form of not quite contract but agreement between third sector and Health Authorities as to how they work together. But I think that previous administration paid lip service to that government initiative, I don't think there was a great deal of detail in that compact and I think it was just there so we could say yes we have done that. Tick the box. So it would need quite an overhaul and doesn't have any relevance to the register with local authority and the third sector. I think the compact is probably not the way to put that down in paper.

NEW SPEAKER: Ian: The compact is pretty much the relationship between the council and the voluntary community sector.

Co-production goes broader than that and it is about how we work together so some of the things in the compact about when you are doing procurement process that you will do it with allowing a

certain amount of time for each stage, so that the voluntary community sector was doing consortium bids that they have enough time to do it and come together and do it. But in terms of the Charter it is about timescales, what are the timescales involved in allowing a sufficient amount of time to go through that process. But it shouldn't necessarily be the council that siewltd set that agenda, it should be the council, maybe one of the partners in that but it should be all of the people. Collaborative.

CHAIR: I'm not advocating for dusting it off, it is whether or not the document has any weight any more. I agree with you, what others have said, what we are trying to do now goes much beyond what compacts were all about now.

NEW SPEAKER: Ian: In other areas the compacts are alive and well and used but I think they are used in a way that is more around a contractual enforcing of a partnership rather than how we work together in a mutually beneficial way.

NEW SPEAKER: Peter. My recollection of the compact, if it is still in place, was it was largely around a desire to see some longer term funding arrangements put in place for third sector. There was separation of those organisations which were put on to a 3 year funding agreement with a rolling review but, think that was the main function of the compact.

CHAIR: Any other questions for Ian.

NEW SPEAKER: Ian. To add to Peter's point, the administration is looking at going further in that, so actually looking at 2, 4 and potentially 10 year agreements for services where you know that there is going to be a need and it will be ongoing for a long time, making some of those commitments longterm.

CHAIR: Making them unbreakable.

CHAIR: I'm sorry, we are short of time now, if you have anything you want to raise directly with Ian, you know where he is. Thank you for your time.

NEW SPEAKER: Adrian: We can't miss him.

NEW SPEAKER: Ian: I will leave cards there.

CHAIR: As you know, we are due to report round about this time next year, but the forming of the recommendations will be happening autumn time, so I think it is definitely making sure that

what we are recommending around co-production crosses over and supports and enhances what you have done already.

NEW SPEAKER: Ian: That is exactly what Kevin and I discussed in terms of it being a set process.

CHAIR: Thank you. In those last few minutes before we come to an end, item 6, update on surveys, events and the housing strategy. I will do surveys. Kevin sent out earlier this week the staff and residents survey for everyone to look at and comment on and there are copies printed out tonight because you were sent out within the too short a time for us to have useful discussion. I think the deadline a week next Tuesday, so I know some of you have started to do that. Conversation with Kevin earlier today and he is thinking that it makes sense to have a separate survey for Councillors and we were thinking, Vivienne whether or not it might be possible to have a meeting with you possibly to think about what that might look like. So we will be in touch about that. That is surveys. I know it falls to this: People would like to have got them sooner, I hope it is going to pay off taking the time to really get them right. And we will see where we get to when they go at.

NEW SPEAKER: Peter. Kevin is not here, but do we have the distribution lists for circulation?

CHAIR: I don't know. Victoria. Also a group of you gathered together last week to start to plan the public consultation event. Victoria, Tricia and Kevin and Jane. You took the minutes. Victoria you will give us a quick update.

NEW SPEAKER: Victoria: Last Monday the 4 of us got together to start thinking in more detail about the public consultation event. First thing we discussed was the aim of the event. We decided it would be 2 overall objectives. First to educate about the concept of co-production, what it would mean in practice and encourage people to put their names forward to be involved in that co-production process and the form it eventually takes and the second objective was to give people a chance to give us their ideas and views about what they want to change in Hammersmith and Fulham and what doesn't work at the moment, what needs improving. Put it into our final report. We thought that there

should be 2 events but have an open mind and if there was a demand for a third we could add a third on later in the summer. We thought one should be in April and one in May. There is no point holding them too soon but we need to publicize them and people are more willing to attend if the evenings are lighter and we thought one could be in the evening, one in the weekend to maximise people to participate. We decided that one venue in Hammersmith and one north of the borough, so we looked at the Lyric Theatre, Saint Peters church for Hammersmith and then the White City community centre for the one in the north of the borough.

NEW SPEAKER: Martin: I want to get involved I have got a possible venue in mind in Hammersmith and Fulham. And it is the pavillion where me and the rest of my guys go to. On Fulham palace road. Pride in Putney.

NEW SPEAKER: Victoria. We will think about which venues work best, we want something central for the Hammersmith one and easy to get to and one that has a high profile so we need to bear that in mind. I would help Kevin and Sarah and anyone else to organise the Hammersmith event, Kevin the White City event. We thought we would aim for, allow enough space for 50 people to attend plus the commissioners and PA volunteers. And the event will be about 2 and a half hours long. Long enough to give people time to contribute but not so long that people get too tired or put off from coming. We want to use every available means to publicize this event. So council websites and other websites, local papers, fliers, posters. Local library notice board. And we wonder if it would be possible bearing in mind these events are in April/May whether we could put a leaflet in with council tax bills. We also thought there ought to be refreshments, tea, coffee, and entice people along. Also thinking about the structure of the event. It would be quite closely structured. What we had in mind was a period of people working in small groups together and then one person from each group feeds back at the end of the session what has been discussed. And maybe a plenary time towards the end to discuss in more detail. We thought we would encourage people to turn up to the event in advance and we need to make sure they

were properly supported by Palantypists, interpreters et cetera so everyone can be accommodated.

[CHAIR INDICATED PALANTYPE COULD END]