Minutes of the 5th meeting of the H&F Disabled People's Commission

Wednesday 1st February 2017 at the Dawes Road Hub

Present:

Tara Flood (Chair) Patricia Quigley Martin Doyle Victoria Brignell Kate Betteridge Mike Gannon David Isaac Ramona Williams

Apologies

Jane Wilmot Ali Buhdeima Cllr Sue Fennimore, Cabinet Member for Social Inclusion Kevin Caulfield, Policy & Strategy Officer (Disabled People's Commission)

Also Present:

Cllr Vivienne Lukey, Cabinet Member for Health & Adult Social Care Henrietta Doyle, Inclusion London Anna Drescher and Adrian Whyatt, HeadsUp Ian Lawry, sobus

H&F Officer Support:

Peter Smith and Fawad Bhatti, Policy & Strategy Team

1. Minutes of the Last Meeting

Tara welcomed everyone to the meeting. It was noted that although Kevin had been unwell, he had been in email contact. Colleagues wished him a speedy recovery. The minutes were agreed as a true record.

<u>Review of actions (including updates from previous meeting):</u>

Tara advised that the survey was on the agenda and related actions (page 2) would be covered then.

Future Waste and Street Cleansing report.

Item 1.8 update (page3). Tara said Kevin had emailed Kathy May twice and was still waiting for a reply, so if a reply comes after tonight he will forward on to people interested in this.

Kevin to contact Safety Net People First regarding work plan and to start to look at developing a Council webpage for the Commission

Item 1.10 update (page 3). Tara advised Kevin had met with colleagues from Safety Net People First and once the surveys have been agreed, he will send on to Martin and Hana. In terms of the minutes of meetings, they are ready to be uploaded up on to the website. Kevin has emailed everyone asking if they wanted anything recorded in previous minutes removed or anonymised. Please let Kevin know by the end of the week, as they will be uploaded on the website soon.

Kevin to contact Lee Fitzjohn (Head of Insight & Analytics) Item 1.11 update (page 3). Tara said that Kevin asked for it to be noted that the help on the surveys from Milan Ognjenovic in the Insight and Analytics Team and Kirsty Langley from Communications had been fantastic. Action: Peter to circulate dates of future HASCSI PAC meetings (Page 4). This has been done.

Action: Draft Strategy on Tackling Social Isolation and Loneliness to be brought to next meeting for discussion to be bought to next meeting.

(Page 5). Fawad advised that this affected not just us in H&F but across London and nationally. The Strategy had been developed following a workshop with the local voluntary and community sector. A group of officers had developed the Strategy responding to issues raised at the workshop and also including good practice elsewhere. The 'high level' Strategy is more or less complete and ready for open consultation with the accompanying Action Plan being worked on currently. A follow-up workshop with voluntary and community groups is also being planned and the lead officer Anna Waterman from Public Health was very happy to deliver a presentation to the Commission.

Peter wanted to clarify, that he had met with Anna who said she would release an up-to-date draft on 17th February. It is probably not ideal because it is still being developed but she said it will be ready by 17th February. After a three-week consultation period up until 10th March she would be happy to come to the March meeting with a revised version for comments.

Tara asked for the Strategy paper to be circulated to Commissioners and then we decide whether or not it would be useful to have someone present to us.

Victoria mentioned that the Jo Cox Foundation is also spearheading a drive to combat loneliness.

Action: Draft Strategy to be circulated in advance of the March meeting.

Action: Kevin to circulate copy of Tom's presentation to Commission along with copy of executive summary. (Page 9). Kevin had assured Tara that this was sent on 4th January.

Action: Kevin to obtain a copy of new Hounslow compact. (Page 13). Tara informed the meeting that this has been done but Ian Lawry will talk about the H&F Compact later, which may be more relevant.

Action: Kamran to forward a web link to Local Voices. (Page 13). Tara said Kevin is picking this up and will circulate afterwards. Apologised that it didn't get followed up sooner.

What will success look like?

Item 4 update (page 15). Tara informed everyone the change had been made and the final version of the document will be circulated.

Action: Commissioners to submit short biographies to Kevin by 15 January.

(Page 15). Tara was the last person to do it but everyone else has submitted them. A couple of people haven't yet sent their photos but Kevin will follow that up.

Peter mentioned there are photos from the recent Mayor's reception for all the H&F Commissioners.

Action: Commissioners who wish to attend the meeting with Deaf PLUS to let Kevin know and Kevin to organise meeting for 5th or 12th January.

(Page 17). Kevin and Ali have tried to get hold of Deaf PLUS but with no success. Kevin has emailed again and will let Commissioners know the outcome.

Following on from Peter's earlier comments, Tara asked Patricia, Ramona and Victoria if they wanted to say anything about the Mayor's reception that happened on Monday night.

Victoria felt it was a lovely evening and it was a good chance to meet and network with people from other H&F Commissions. Also presentation of plaques to Commissioners was quite special. Along with Patricia, she had a long chat with Cllr Steve Cowan after the presentation.

Patricia was also impressed with her plaque's Latin motto and enjoyed meeting the Mayor.

Peter stressed there were enough plaques for all members of the Commission and he would be delighted to provide them to those who were unable to attend the event.

Victoria said a photo with the 3 Commissioners and Cllr Cowan will go on the Commission website.

Ramona loved her plaque and found it interesting meeting people involved in all the different Commissions and seeing how they have come on from when they first set up.

2. The reality for Disabled People across London

Tara introduced Henrietta Doyle from Inclusion London.

Henrietta first spoke about the work of Inclusion London, a disabled people's pan-London, pan-disability organisation providing support to local user-led disabled people's organisations in London. They also took on strategic court cases related to the Equality Act and the Human Rights Act. When Kevin informed Henrietta about this Commission, she felt it is really something different, being based on the UN Convention on the Rights of People with Disabilities and policy formed from disabled people's experiences. She congratulated commissioners for championing a new way and for having had some successes already.

Some pointers for success regarding co-production from her colleague Tracey Lazard would be shared at the end of the presentation based on her experiences in Islington. Henrietta's role as policy officer is to provide responses to enquiries and organise consultations as well as supporting disabled people's organisations.

There are about 1.2m disabled people in London, and 12.2m disabled people in the UK, about 19% of the population. 48% of households with disabled people live in poverty. Disabled people have a higher risk of poverty and the big issue is the Welfare Reform Act 2012 and the Welfare and Employment Act.

One of the issues that disabled people find very difficult is the work capability assessment and the personal independence assessment. The assessment eligibility criteria was narrowed and this is hugely frustrating to disabled people's organisations because they are so inaccurate. The report that the assessor gives often doesn't bear any resemblance to the information that the disabled person has given in the assessment.

The National Audit Office has said that only 13% of Personal Independence Payment (PIPs) assessments and work capability assessments reached the required standard, so that means 87% are below standard. People now can't directly appeal, they have to go through a process called 'mandatory reconsideration' and for the majority of people the decision isn't changed. A lot of people drop out at that point, even though 58% of appeals are successful. With the change of eligibility criteria, many people are losing Motability vehicles, 700 people a week across the UK. Because of the narrowed eligibility criteria (changing the distance that you can walk to 50 metres), 350,000 vehicles were returned in 2015. In many areas public transport isn't really accessible leaving many marooned at home.

Another key issue is the 'Bedroom Tax' which causes difficulties because often there isn't accessible accommodation available to move in to. Sanctions are having a massive impact on those that they are applied to. Henrietta cited a recent example of an autistic young man on Job Seekers Allowance looking for work, given benefit sanctions because he couldn't fill in the forms, because of his learning difficulties. Reasonable adjustments were not made. The sanctions had a devastating impact on his mental health and it has been recognised by the National Audit Office that sanctions don't work. People face eviction or are forced to use food banks because of this incredibly destructive policy.

Freedom of Information requests have revealed that people with mental health support needs and learning disabilities receive the most sanctions. Sometimes sanctions are handed out when someone has been 15 minutes late for an appointment.

Nationally, 1,749 employment support sanctions were actioned in June 2016. The highest in a month was in June 2014 with 2,695. £4.6billion has been cut from what councils get for social care over the last 5 years.

The Independent Living Fund (ILF) has been devolved. A colleague Ellen Clifford had done a recent survey which revealed across London, ILF was very much a postcode lottery. For residents in H&F and 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.

Regarding disabled people and employment, 'Access to Work' was still a good scheme overall but people can experience funding cuts. Deaf people whose funding has been cut are sometimes not informed of the cut, so they continue employing British Sign Language (BSL) interpreters that they need as normal and then find they haven't got the funding. Henrietta was very happy to share her presentation as it contained key statistics that the Commission could use for their purposes.

Victoria added that the government is imposing caps (£41,000) on how much you can claim which affects deaf people because of BSL interpreters.

Action: Henrietta's presentation to be shared with minutes

Concluding her presentation, Henrietta shared the key elements for success for the Commission as proposed by Tracey Lazard, the Chief Executive of Inclusion London. This was based on 6 years of experience working in Islington and a similar exercise they had undertaken there:

- It was crucial to have leadership buy-in right at the top. In Islington the Deputy Director (of Social Care) chaired meetings and the relevant director to whatever policy that was under discussion also attended meetings.
- Also the need to have an agreed process for co-producing and scrutinising the policy being discussed at each quarterly strategic meeting (out of which came an agreed action plan).
- Islington focused on a different policy at each quarterly meeting and key issues identified were put into writing and sent to the relevant director. The director then responded with

what would be done in reparation before the next meeting where whether a difference was being made was discussed and agreement reached.

- New policies were also developed as well as reviewing existing ones. Some of their wins included the finance department starting to produce council tax information in easy read and plain English and the housing department agreeing to provide visual warning mechanisms for door bells for deaf residents.
- Finally, adequate support for all meetings such as BSL and a Palantypist, which is already in place here. The organisation Independent Living in Scotland has produced a co-production toolkit and there is a link to it in the presentation she will share.

Patricia said that Employment and Support allowance (ESA), PIP along with other benefits were calculated on a points based system, where you might have three or four different sub-answers to give responding to a question. So on one of them you might score low and then in another one you might score high. They don't see the person as a whole and it is just a 'numbers' system, where to get the benefit, if you are over the threshold by just a few, then you are just put to one side.

Henrietta agreed the scoring systems don't see you as a person and they need to be based on the Social Model of Disability. E.g. ESA doesn't recognise the barriers that disabled people face regarding employment, or takes into consideration the attitudes of employers. The Welfare Reform came about because the government wanted to reduce the number of people on benefits.

Patricia related to how careful people had to be because a couple of years ago she had filled in a form for ESA but had answered a question the wrong way. She was asked if she could do something and had honestly answered yes. Luckily she asked someone to read the form before she submitted it and the question was actually could you do it 20 or 30 times, to which her answer was no.

Last year Ramona had met with Colin Morris from the Department of Work and Pensions (DWP) for West London at Action on Disability. She had information on how PIP is scored and what questions they ask but Colin had said half the people that do these assessments are not fully qualified. The only time someone is qualified to do the assessment properly is when you go to appeal. Also when you go to the assessment they also encourage that you take an advocate because sometimes as a disabled person you will say yes to everything they ask you and the reality is you can't really do it.

Kate asked Henrietta if there is anything particular about London that makes the experience different for us compared to the rest of the country.

Henrietta responded that because housing costs have risen so much in London, there is a lack of accessible housing. There are higher numbers of people with mental health support needs in London and numbers are rising.

Tara thanked Henrietta for her fantastic presentation to the Commission and asked if any follow-up questions could be sent to her. Also asked if was there is any potential for this Commission to feed into anything the Mayor of London is doing with the new Greater London Authority (GLA) London Plan.

Henrietta said she would be happy to provide any supporting information that is useful to the Commission and would follow-up with Tara outside the meeting with regards to connecting with the Mayor of London's Office. Adrian thought the figures for the number of disabled people were far too low.

3. Presentation from local disabled people's organisation (DPOS) on how local disabled people take part in decision making

Anna introduced the H&F HeadsUp project which is about co-production around mental health. HeadsUp have a network of a thousand service users who attend service engagement activities and are involved in co-production. They have a number of primary and secondary care mental health service forums where service users feedback on the particular service they are using, suggesting what could be done to improve it and then this is passed on to relevant people. The HeadsUp committee is a group of 10 service users who meet once a month and hold the local trust to account to making sure they are doing co-production.

HeadsUp also offer to place service users on interview panels and also service users attend trust meetings. Also provide training to their users to enable them to participate more effectively. Anna then handed over to HeadsUp member Adrian.

Adrian shared his many experiences over the years with service user forums and spoke about HeadsUp's successes across London in which he has been involved. One was the setting up of a peer support group, a user-led entirely self-funded organisation that has met at the London Action Resource Centre at Whitechapel since 2012. With the support of the fire brigade as well, people continue to meet as a peer support group and help a number of people.

HeadsUp has also enabled people to participate in research and treatment initiatives which otherwise they might not be able to take

part in.

Adrian spoke about the Recovery College at the West London Mental Health Trust, where he is a peer trainer there and along with other service users. As far as he is aware this is the first Recovery College to do a course on acquired brain injury which he helps to co-deliver. The College also delivers courses on various subjects, from autism to getting benefits and dealing with the system. For some conditions like personality disorder they do have a social interaction training programme which is free to access.

However, Adrian advised there are areas where user involvement and co-production could improve and highlighted the fact that there is no consistency and no genuine involvement for service users in regional and national services outside of the things done by West London Mental Health Trust. Outside the Greater London area, there is the Discovery Centre for Dyspraxia in Cardiff. This is the main centre nationally and was set up by someone who has dyspraxia herself.

West London Mental Health Trust is responsible for Broadmoor but service user engagement isn't always consistent. When Adrian and HeadsUp colleagues went there for an involvement day there was no involvement of inpatients at the event.

He felt that unlike some other boroughs, Hammersmith and Fulham Clinical Commissioning Group has failed to commission any specific services for long term survivors of brain injury and also don't appear to have anyone with any expertise in the area. There is a problem with the lack of any funding for user-led organisations in this area.

Amongst sharing many other examples, Adrian referred to Buckinghamshire where they have a comprehensive brain injury service which is recognised as best practice. There are other areas like Cardiff where they have very good provision for specific learning difficulties.

Thanking Adrian for his presentation, Tara asked colleagues for questions for him and Anna and started by asking if there was a policy that could be shared with us that sets out the commitment to co-production drafted by Heads Up or West London Mental Health Trust. It would be useful to see that.

Anna replied that they do have guidelines on how to involve patients and service users in everything they do, especially meetings and interview panels and how they consult on various strategies. She will send these on to Tara.

Mike asked if the Committee was a focus group.

Anna responded that the Heads Up Committee is a group of service users who meet up every month and she explained how they operate.

Mike had discussed co-production approaches when he met David Burns (Head of Housing Strategy) along with Jane on 21st January, and the question of co-production came up. One way could be for people to be almost embedded with the teams, more of a direct involvement.

Anna advised the HeadsUp committee members more or less do this when they take part in various meetings or steering groups like the Implementation Group for Adult Social Care. HeadsUp is more about user involvement, although co-production is promoted and facilitated. However, the user-group West London Collaborative, founded by the West London Mental Health Trust, do pure co-production. Their Chief Executive was an inpatient.

Adrian offered 4 brief recommendations to the Commission that

could be adopted quickly:

- Hold meetings in all parts of the borough as some people with mental health conditions can't go beyond a very local area and may have travel difficulties. 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.
- The Commission should be looking at peer support groups, creating them around the borough, around hubs of communities.
- Help people to get online and use technology to promote people's rights. A lot of people with mental health issues (over 90%) spend too much money when they are going through a crisis then end up in debt.
- Cater to the needs of groups, such as promoting the provision of alternative colours of screen and 'universal' design principles.

Ramona referred to Adrian mentioning sensory impairments. Visually impaired people can also have mental health related issues because some do become isolated. She wanted to clarify that visually impaired people will have a variety in what screen colour combinations they prefer and you can't always please everyone.

4. New ways of working together locally (co-production)

Tara introduced Ian, the Chief Executive of Sobus (social business) to talk about the work his organisation was doing to develop co-production locally.

Ian offered some background to Sobus to Commissioners. It provides support to the voluntary sector, ranging from one-to-one advice for groups, support around premises and meeting space as well as support to access funding. E.g. Sobus has been setting up a grants programme funded by the H&F Clinical Commissioning Group (CCG). He said he would refer to a report summarising the co-production work which went to the Health, Adult Social Care and Social Inclusion Policy and Accountability Committee (HASCSI PAC) earlier in the year.

Ian mentioned the good links Sobus has with the CCG, the Council as well as local organisations such as Action on Disability, with whom Sobus were developing a joint bid to engage disabled residents around their employment needs in the emerging regeneration area in the north of the borough.

The work on co-production outlined in the report resulted from the need to look at how services can be redesigned so that they are more effective both in terms of meeting needs of service users but also in terms of cost pressures. Co-production has been supported by ClIrs Lukey and Macmillan (Cabinet Member for Children's Services) and a working group which was made up of council officers, voluntary sector organisations and local residents. They looked at ways of redesigning services so there was a framework to it and it was service user centered.

Not just around how services are designed but also delivered. Co-production 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 processes as active parties. There are 6 key principles within the report which were piloted in 3 areas: the Youth Partnership, the Carer Support service and the Supported Employment Service. The Council is currently going through the Integrated Family Support Service (IFSS) process which builds on some of the recommendations in the Sobus report. Learning from the pilots show that it is important that when you are wanting to change services, you have a shared vision as to what you are trying to achieve. If you're not all trying to get to the same place, it ends up a bit messy. A really good understanding must be established as to who is going to be part of that process and the roles that those people play in that process. Ian proposed 3 further recommendations for the Commission to consider based on the learning from the pilots.

It is vital people are trained to participate in the process so they have the right knowledge at the outset, saving time taken for 'on the job training' which slows down the process.

Having somebody to facilitate the process will certainly enable the work to move more quickly.

Resources identified to support people to be involved in that process. Sometimes it is financial and you have to consider how certain users might want to be engaged, e.g. young people may not want to attend a typical daytime meeting. Also it's not necessarily about long surveys in engaging users but sometimes quick questions, like on twitter, yes or no answers on a regular basis over a period of time. So that you have got ongoing engagement in the process.

Ian stressed the point about securing the commitment from all partners to the process and the sign off at key stages by all partners where it is needed.

Ian mentioned that there is a plan for the working group to come back together and consider the next steps along the coproduction journey in H&F. A co-production 'charter' had been discussed. Each time it should be a reflective process taking in lessons learned from the last process and feeding it into the next process. Kevin has been invited to join the working group. If he is not available than someone from the Commission is welcome to participate.

Tara appreciated lan's presentation and asked if anyone had any questions.

Adrian wondered what could be done in getting the consideration of disabled people into self-employment as part of supported employment service co-production discussions.

Ian replied that in terms of truly holistic co-production, it shouldn't be driven by a specific service needing to be commissioned differently but by what the needs of our local residents are and how we respond to those needs.

Ramona shared her personal experiences about being self-employed because as a disabled person, getting into work is quite difficult. She had been on many, many different employment programmes and often gave up. She asked if Sobus are doing any work in this area.

Ian responded that Sobus are not specifically doing anything around employment support for disabled people but he mentioned the proposal looking at what services are available for disabled people around employment and how they can engage with disabled people in terms of shaping that in the regeneration area. Sobus doesn't work directly with residents and service users.

Tara informed Ian that at the last Commission meeting, Sarah and Kamran were here from Action on Disability and we talked about definitions of co-production and Sarah mentioned compacts. She asked Ian to share what he knew about the Hammersmith and Fulham compact. Ian believed there is or was a H&F compact but it isn't referenced on a regular basis. Adding that other boroughs will have a compact, where mutually the council and the voluntary sector are holding each other to account. For some, the compact is a preset description of how we are going to work together.

Tara asked for clarification on status of the H&F compact and whether it was a 'live' document.

lan was not able to confirm.

Cllr Lukey didn't think the Council administration has looked at it since coming into power. Initially everyone had to do it because the government said you have to have these compacts. This administration could revive it but she would question the point of having a document if no one actually uses it.

Peter recalled that the compact was in reaction to a previous government initiative to try and get some form of an agreement between third sector and local authorities as to how they work together.

Ian felt the compact is pretty much about the relationship between the council and the voluntary & community sector. Co-production took things to another level.

Tara did not advocate dusting it off but wanted to know whether or not the document has any weight. Agreed with what others had said and surmised that what we are trying to do now goes far beyond what compacts were all about.

Ian repeated his earlier point that in other areas the compacts are alive and well and 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. Peter recollected that the compact under the previous administration was largely developed around a desire to see some longer term funding arrangements put in place for third sector organisations.

Ian added that the current administration is looking at going further in that: 2, 4 and potentially 10 year agreements for services where you know that there is going to be a need for a long time.

Tara informed Commissioners that the final report is due about this time next year, but the forming of the recommendations will be happening autumn time, so we need to make sure that what we are recommending around co-production crosses over and supports and enhances what Sobus and colleagues have done already.

5. Update on surveys / events / housing strategy

Tara started with the update on the surveys. Kevin had earlier this week sent out the staff and residents survey for everyone to look at and comment on. The deadline was Tuesday 14th February. Kevin thought it made sense to have a separate survey for councillors and suggested a meeting with Cllr Lukey to think about what that might look like.

Tara asked Victoria to report on the meeting last week to start planning the public consultation event. Victoria, Patricia, Kevin and Jane met to discuss.

Victoria updated colleagues on this meeting held on Monday 23rd January. Colleagues discussed clarifying the aim of the event and people agreed there would be 2 overall objectives.

The first objective was to educate residents about the concept of

co-production. What it would mean in practice and to encourage people to put their names forward to be involved in that co-production process.

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 tell us what doesn't work at the moment, what needs improving so we can put these views into our final report.

Thought that there should be 2 events but have an open mind and if there was a demand for a third we could add one later in the summer. Proposed one should be in April and one in May. We need to publicise them and people are more willing to attend if one could be in the evening mid-week and one at the weekend.

Colleagues also decided that one venue should be in Hammersmith and one in the north of the borough. The Lyric Theatre or Saint Pauls Church in Hammersmith and then the White City Community Centre for the one in the north of the borough.

Martin proposed a possible venue: the pavilion on Fulham Palace Road, Putney.

Victoria said the planning group will think about which venues work best, somewhere easy to get to for residents and one that has a high profile and is well known.

In terms of each event, aim for and allow enough space for 50 people to attend plus the Commissioners and PA volunteers. The event should be about 2 ½ hours long - long enough to give people time to contribute but not too long that people get too tired or put off from coming.

Every available means to publicise this event should be used: council and other websites, local papers, flyers handed out and posters put up, e.g. the local library notice board. Also proposed putting a flyer in with council tax bills. There ought to be refreshments, tea, coffee to entice people and the event would be quite closely structured.

People working in small groups together and then one person from each group feeds back. Maybe a plenary time towards the end to discuss in more detail. We would encourage people to turn up to the event in advance and we need to make sure they are properly supported by palantypists, interpreters, etc so everyone can be accommodated. These are the Commission's main public events so need to be planned and delivered well.

The next events planning group meeting is Tuesday 7th February at 6:30pm at Kevin's residence.

Ramona requested that visually impaired people be considered when designing promotional materials.

Mike updated Commissioners following his meeting with David Burns on the Housing Strategy. He felt that there were some questions David couldn't answer and hoped to meet with him again soon. E.g. when a disabled person leaves (or dies in) an adapted property, what happens to the accessories. Advised that accessible housing would be included in the 600 affordable homes being planned.

Cllr Lukey added that the council will be communicating with residents on the housing stock transfer later this month and will inform Tara when this will be.

Mike shared his personal reservations on the transfer.

Tara felt it would be a good opportunity to test co-production with the new Housing Strategy and that this should be explored.

6. Any Other Business / Dates of Future Meetings

Tara informed colleagues that she will be meeting Bathsheba Mall from Committee Services to see how the Commission can fit into the work programme of the HASCSI PAC.

Tara said that some dates of future meetings will need to be adjusted and she will liaise with commissioners by email.