

**Minutes of the 8<sup>th</sup> meeting of the H&F Disabled People's Commission**

**Thursday 18<sup>th</sup> May 2017 at Dawes Road Hub SW6**

**Present:**

Tara Flood (Chair)  
David Isaac  
Martin Doyle  
Patricia Quigley  
Ramona Williams  
Victoria Brignell  
Jane Wilmot  
Ali Buhdeima  
Kate Betteridge

**Apologies:**

Mike Gannon DPC Commissioner  
Cllr Sue Fennimore, Cabinet Member for Social Inclusion  
Cllr Ben Coleman, Cabinet Member for Health and Adult Social Care  
Peter Smith Head of Policy

**Also present:**

Jane McGrath, West London Collaborative  
Sarah Thomas, Interim Director of Delivery and Value

**H&F Officer Support:**

Kevin Caulfield and Fawad Bhatti, Policy & Strategy Team

**1. Introduction**

Patricia began the meeting as Chair, as Tara was delayed. She informed the meeting that Cllr Vivienne Lukey will no longer be attending DPC meetings as her Cabinet portfolio has now been taken over by Cllr Ben Coleman.

## **2. Minutes of 7<sup>th</sup> Meeting**

Previous minutes were agreed as an accurate record.

### **Review of Actions**

Kevin to contact Anna Waterman with regards to the draft Social Isolation & Loneliness Strategy.

Still to be done as Anna had changed jobs recently.

Tara to meet Bathsheba Mall about the DPC fitting in to the HASCSI PAC work programme

This meeting took place on Friday 21<sup>st</sup> April and there was a good discussion. Patricia and Kevin were also present.

Clarification around Deaf Plus funding from H&F Council.

Kevin confirmed that DeafPlus is funded to work in H&F up to 2018 with a grant of £18,000.

Jane to submit questions to SNPF on health care (commissioning) issues.

This has been done.

Milan to circulate DPC presentation on data and surveys.

This has been done by Kevin.

Milan to separate accessibility of home care and restrictions on adaptations and provide further information on each.

Kevin needs to meet with Milan.

Milan to find out more about staff responders, their departments / services and whether they were frontline staff.

This is not possible to do as the questionnaire did not ask respondents to identify whether they were frontline staff.

Milan to provide final summary analysis of surveys for the May meeting.

This has not been provided in time to circulate with today's meeting papers.

Tara to email commissioners about the Final Report Working Group  
Done.

Kevin to circulate proposed headings to interested Commissioners  
Kevin advised this is an item on the agenda.

Commissioners were asked to provide Tara with their availability for the 29<sup>th</sup> event.  
Done.

The minutes were approved as a correct record with one correction. Dave's surname is Isaac not Isaacs.

### **3. Discussion from 29 April event**

Kevin felt it was a really good event and people wanted to work together to move things forward. Issues discussed included access to welfare benefits and education about people's rights, housing and social services. Many of these had already been gleaned from the resident's survey. 13 / 15 people who provided feedback were "happy" or "very happy" with the event. Comments included "a good start" and "well done".

Dave said that people on his table were happy to be there. The overall impression was that people were willing to "listen" to them but also concerns that they may not be "heard" and that

people would just go away and do what they were going to anyway.

Ali felt there was a really good atmosphere and it was great to meet new people and share information. Felt that things will get better in the future.

Jane thought it was a great event with a wide range of views expressed by disabled people.

Martin couldn't attend and had sent his apologies.

Ramona advised the event went well and there was a good turnout. People with different disabilities had similar views on things.

Kate mentioned the great atmosphere with good discussions at her table.

Victoria was pleased with the number of people who came. Many people expressed their negative experiences but were positive about moving forward. Felt co-production could work well.

Patricia had a really positive day. Felt that commissioners have been given a good opportunity to do something around co-production.

Tara said well done to the planning group and was a really unifying event but now felt the pressure on getting things done as best we can. Tara proposed that we find a way of perhaps funding smaller events for marginalised disabled people rather than another large event like this one. Also she proposed a follow-up event to talk to people about our recommendations. There was a gap between the council's Senior Leadership Team meeting at the end of July and the HASCSI PAC where this event could be held.

Kevin had been asked if we can make a video and put it on the website. Sarah offered to talk to the council's Communications Team to help with the video message.

Jane mentioned that someone should be developing relationships with people who wanted to stay in touch.

Tara noted that there were a lot of people on the 29th who said they wanted to stay in touch and assist in informing the Commission's work. Kevin noted that there were another 15 people registered to come who didn't come for various reasons, but all those people are also interested in doing something more. Tara noted that the group may provide a useful pool for co-production.

Victoria announced that sometime in the next few weeks AoD will be sending out letters to all of its members to advertise its AGM so if a date is fixed for the Autumn public event before then it could also be advertised in that letter. Tara suggested that someone from the Commission might speak at the AGM.

**Action:** Kevin to fix date and book venue for autumn public event.

#### **4. Update: Disabled residents survey data analysis**

Kevin reported that there were 32 survey questions and that there had been 158 responses to the residents' survey so far, and it is still live until the middle of June. He drew attention to the finding that 61% of respondents said that their quality of life had gone down in the last year. Only 4 per cent of people that replied said their quality of life had gone up.

Some of the comments give reasons for this, e.g.: "I no longer have the support of a carer"; "I'm being forced to work again, my life is extremely stressful"; "My health is deteriorating while

my income is stagnant and living costs are rising”; “I'm worrying about re-assessments for DLA/PIP and ESA”.

Kevin also noted that 77% of people said they get some form of support but it was interesting that 40% said that their support comes from family and friends. 30% of respondents were in education, employment or training, but only 14 per cent were in some form of employment, and 21% were people who identified as being retired.

**Action:** Kevin to circulate summary of staff and residents' surveys.

**Action:** Kevin to post councillors' survey online once final questionnaire is agreed.

## **5. Update on Co-production**

David gave a presentation on co-production. The Care Act 2014 states that local authorities, where possible, should actively promote participation and that co-production is when an individual improves services received or groups of people get together to improve the way services are delivered. The definition isn't as helpful as other definitions. It only talks about people who use services rather than working with people in partnership. It emphasises the range of activities that include co-production and makes it clear that it is primarily people who use the services, carers and communities that should be involved in co-production. Implementing co-production is challenging and complex, looking at every aspect of how an organisation works.

Co-production is a slippery concept and if it is not clearly defined. An important part of the process of co-production is for organisations and projects to come to an agreement on what they understand co-production to be and the principles that would guide its implementation. Co-production is not just a

word, it is not just a concept, it is a meeting of minds coming together to find a shared solution. In practice it involves people who use services being consulted, included and working together from the start to the end of any project that affects them. Co-production should be a coalition, both service user and provider treated as valued equal partners in all decision making.

Co-production has been tried without any real success since the 1970s. David noted that earlier this week he had attended a meeting with Sobus to discuss local co-production. After reading the draft charter they had tried to achieve similar goals to the DPC and after 2 years of trying and some very good work they still don't have a working model. So where is everyone going wrong or are we trying to kid ourselves that it is even possible?

How to put co-production approaches into practice in organisations and projects.

Model for management of change is best described as 4 pieces of a jigsaw:

- Culture, the belief and values that define an organisation and the ways that it works;
- Structure, the way an organisation is arranged and how it is set up to carry out the work;
- Practice, how an organisation and people work together for it to carry out their work;
- Review, how the work is done and the outcomes and impacts as a result of that work.

The whole system approach is needed because organisations must change at every level from senior management to frontline staff if they want to achieve meaningful participation. Participation should be part of daily practice and not a one-off thing.

Values and behaviours: For co-production to work we need to create a culture where the values and behaviour are the norm. The idea of co-production needs to be accepted and supported by everyone. Honesty and cooperation is paramount. There needs to be a commitment to sharing decision-making. Communication needs to be clear and transparent and everyone's opinion should be valued and respected.

Implementation: For co-production to work, the first thing that is needed is for full cooperation from all senior leaders. A team of full time commissioners as well as a diverse team of volunteer commissioners need to be set up. This team must be involved in all decisions at the time of conception. At the moment most people are asked for their opinion a week or so before the meeting. It doesn't give you time to give a considered and thought out opinion. The team must be accessible to the public, care users as well as care givers, as they will represent the user. A good dialogue, listening and hearing what is needed and continuous reviewing is essential. The relationship between co-production teams/departments and decision-makers, senior management and frontline staff must be continually built on so that involvement becomes the norm and regular training between users, frontline staff and co-production teams so that everyone knows what co-production is and how to implement it seamlessly.

David circulated a paper setting out a co-production model that was produced for NHS England.

Kevin reported back on a very useful meeting that the Commission has had with housing officers that has begun to establish a co-production process for developing a new housing strategy for disabled people in Hammersmith & Fulham.

Kevin also reported that Hammersmith and Fulham has agreed to co-produce and develop an adult social care personalisation strategy. He explained that the DPC has agreement to



commission the direct payment support service as a co-produced piece of work.

Kevin also reported that Victoria is writing a blog on democracy and co-production for co-production week, which is 3-7 July, and that he is organising an event for H&F staff, off the back of the survey, for those that expressed an interest in being involved in the co-production network.

**Action:** Kevin to organise H&F staff event on co-production.

6. Presentation: experiences of co-production and working alongside disabled people. Jane McGrath, West London Collaborative

Jane McGrath began with a brief history of West London Collaborative (WLC), which came about through West London Mental Health Trust and general anger that service users were not being given an equal say and involvement was tokenistic and paternalistic. It was a lot of really angry people always raising a fist at staff. So it came about as how we can have fewer arguments and try to work together. An investment of £150,000 a year over 3 years to set up the West London Collaborative, to be run and owned by people from the community across Hammersmith and Fulham, Ealing and Hounslow. It was set up as a community enterprise company, focussed on co-production.

Jane said that what she didn't realise three years ago was that people would replace the word 'involvement' with co-production and they would tell everyone that they were doing co-production with the Collaborative but co-production is very different from consultation.

Jane recently wrote a blog for the King's Fund and called it Co-production - an Inconvenient Truth, in which she asked the following questions: Does it work in practice? What have we

learned as an organisation? Key themes that came up were around empowerment. Most institutions, such as local authorities and the NHS, are very hierarchical, but by its nature co-production is networked and non-hierarchical, so hierarchy is a real barrier.

Also really important is: Conflict, disagreement and how you reach resolution, because this isn't always pleasant. Although people say they want to co-produce with you, what happens when they disagree with what you want or what you have said?

The other key is assumption: People making assumptions about each other and what each other want and that can happen not just with the 'us and them' but with the 'us'. We all want different things, we don't all agree. So when you actually get disagreement within the cohort of collaborators, people say, "You can't even agree amongst yourselves, how are we ever going to get anywhere?"

One of the key learnings was around reflective spaces and making time to reflect on where the power sat in a meeting: who spoke and who didn't. Challenging someone who has been in authority for a long time can be a very painful process.

Other key points are evaluation: if you don't evaluate you can't prove it and you can't get it funded again, so we have had to be very careful about our evaluation. The other word that always comes up is assets. We have all got very different skills and sometimes you don't have all the skills that you need in the group or the room and you have to go out and find them.

Jane gave an example of a project with Imperial that was done on an intensive care ward. Most people might think 'how can you possibly co-produce and power share in an intensive care mental health ward'? The WLC designed or co-designed how to do that with the people who were on the ward and what they learned is that a person's illness fluctuates throughout the day

and you can always grab some time with someone if you are there a lot of the time. So they learned lots of ways of working with people who can't commit to be there when you want them to be, but you have to be very flexible. That was a patient safety project and the learnings were not life changing, but they were for the people on those wards.

There were things like people wanted to have more spaces where they could be alone; carers wanted to have more time to spend on the ward as an observer. They just wanted to come and be with their loved one during the day, not at particular times. The most successful WLC co-production examples have been around urgent care pathways, where they have tried to look at the power imbalance using social media.

Jane completed her talk by saying that WLC is moving its work with co-production around health democracy. She emphasised that there is still a problem with co-production in that it only includes the people who are there to co-produce. She questioned how to involve people who can't get out of the house and said that is what the WLC is looking at in the next part of its work, which is around wider democracy.

Jane was asked how the health democracy work is working and she revealed that it is not. It is repeated research that she is doing at the moment but NESTA has published a paper on health democracy and it talks about pilots around Europe.

In response to a question from the Chair, Jane said that she has come to realise that a perfect co-production world does not exist. She said that she has buy-in for WLC's co-production from the chief executive of a big mental health trust, the chairman and probably 60% of the board but still lots of people don't want it and don't get it. You have to go out with what you have got and just work in the real world with it.

David questioned whether there is an agreed definition as to what co-production is. Jane referred him to the six principles of co-production as defined by NESTA.

Tara asked if Jane and WLC colleagues could help and look over the draft recommendations. Jane was happy to do this.

## **7. Discussion: Final report**

Tara asked commissioners to look at the list of proposed headings for the final report that she and Kevin have produced. She suggested including case studies from the surveys to tell the human stories about disabled people in the borough. She agreed to send an email to all commissioners with a deadline for responses.

Jane asked for a copy of David's presentation and it was agreed that this would be circulated.

**Action:** Kevin to circulate David's presentation.

Tara asked Kevin to identify those who responded to the survey who might agree to be interviewed in more detail to provide case studies for the final report.

**Action:** Kevin to email survey respondents to identify potential interviewees.

## **8. Dates of Future Meetings**

Mon 19 June, Dawes Road Hub, Fulham

Tues 11 July, Small Hall, Hammersmith Town Hall

Tues 12 Sept, Courtyard Room, Hammersmith Town Hall