



Getting Things Changed

Newsletter

February 2016

As the various strands of our project go 'live', you may think there is less to say about the central things that bind us together. But that's not entirely true!

Keeping the conversation going



We now have Vicky Mason working one day a week, on various aspects of the project. But one important thing which she has done for us is to start setting up the webinar arrangements, for us to talk about our ideas with a wider group of people. We had a pilot on February 11th, with three volunteer participants – with activist, family, education and international backgrounds. Thanks to those who took part! I think what we learnt was that specific examples of disabling practices are happening all the time, and that they provide a focus for us to discuss change. For instance we talked about the example of a woman whose bus pass was taken from her by a driver who did not believe

that reveals about judgements, power and normalcy.

The plan will be to present something about our ideas on change, and to discuss

she was disabled, and what examples and reactions with people from

DPOs and others who may be interested. When we do it for real, we will start with a webinar on the project itself, so people can understand what research we are doing.

Vicky has also started producing easy information about the project for people with learning disabilities, and is planning to carry out some focus groups around the country in self-advocacy organisations.

Writing and reporting our outcomes



The three Ideas Briefings that we produced as a result of Phase 1 of the project have now been finalised and are up on our website, and also a new blog 'think piece' from Stan Blue. It is great if we can keep writing, as it does help us to keep thinking



about the main goals of the project. It is currently the 'Research Fish' period, when Val has to submit a portfolio of what we've done so far, and it's looking quite healthy, with blogs, briefings and presentations from workshops (deadline March 10th)

At the end of each of the Ideas Briefings, there are questions – they will help us to keep focused on the points about change which we're wanting to address:

- Can social practice theory help us to understand the way disabled people experience barriers in different areas of life?
- By disabled people taking action, and 'co-producing' change, can they shift and change the way social practices are shaped?
- Is social practice theory enough, or can we make links with ideas about exclusion and inclusion, and power or inequality?
- What will it take to move from theory to implementing practical change, so that we can apply it to make sure that policies do make a difference?
- Can conversation analysis help us to understand the problems faced by disabled people in accessing respectful care and support?
- What is co-production and how do we recognise it when we see it?
- What conditions and contexts help coproduction to strike at a deeper

level, in order to really make a change to the way things are done?

- How can we understand the way power is embedded in institutional practices, and how can power be equalised at micro or macro level?

Update from Strands

Strand 1: Getting Good Support.



Although it's early days, there's so much we're learning here already. For instance, the interactions around people with dementia draw on exactly the same resources as any interaction, but what doesn't 'fit' for them is the pace, and also maybe the way people may switch topics to ask about things that are not currently in mind.

Co-production: We have been working with a Bristol based theatre group (The Misfits) led by people with learning difficulties. They have helped us enormously so far and it have been great fun working with such a talented and gregarious bunch of people. So far, they have produced a recruitment video for us, and we are also looking forward to working through the data with



them and getting their feedback on the interactions.

We have also been forging links with a group called 'Forget-me-nots' in Swindon for people with dementia. We met them recently and it was a real opportunity to learn about their experiences and to get their input into the project.

Data collection: We have started piloting data collection and have filmed one young person and her PA very recently (about 2 hours of footage). This was a great chance to see how the logistics of the project would work. We are all very excited about the acquisition of a wonderful new video camera, a Canon Legria Mini X HD Camcorder. It is far more discreet and unobtrusive than most cameras, and with excellent sound and visual quality.

Strand 2: Changing the Academy.



On 23 February, we held a meeting of those students who had responded to our call for people to be co-researchers in the project. Six people turned up – one participated via Face Time. In addition,

Bernie Munoz Chereau from GSoE, spoke about

Evernote, which is the app that we are suggesting that co-researchers use to 'record' their reflections on their experiences as disabled students in UoB. The group was clearly interested in being involved as co-researchers, not only to share experiences but also to decide how to do the research. Our next step will be to encourage them to publicise the research among their networks as, ideally, we would like to work with a group of 10 – 12. We can then organise the first co-researchers' group meeting – and begin!

Strand 3: Reasonable Adjustments



The Health strand of the Getting Things Changed project has been working on four areas over the past few months.

The first is an audit of Care Quality Commission 2015 inspection reports of hospitals in England to assess their provision of reasonable adjustments for disabled people. This is ongoing work, but we have found already that the term 'reasonable adjustments' is rarely used, and any adjustments that are discussed are very much focused on either people with learning disabilities or dementia.



The second is a freedom of information request to hospital trusts in England to assess their adherence to learning disability care requirements as described by Monitor (see p. 56-57 in pdf below). We have received a number of responses from hospitals, and will be collating the overall findings of these shortly.

Following ethical approval which we now have, we will soon be conducting a survey of patient views and experiences via individuals associated with Healthwatch, as well as professionals involved with patient experience in hospitals.

Finally, we have been organizing advisory groups to help us with the research ideas. We plan on creating two groups: a learning disability consultation group made up of adults with learning disabilities, and a pandisability advisory group made up of disabled people and interested professionals.

Strand 4: Successful Parenting



A meeting with members of Greenwich Advocacy took place in November, and members of the group will contribute to our parents' Advisory Group. In January, Wendy and Nadine also had a very constructive

meeting with members of 'Speak Up Rotherham', a self-advocacy organisation, who have agreed to contribute to the project as part of our children's Research Advisory Group.

Following ethics approval, which we now have for this strand, we are planning to find out about the teaching and learning provided in social work qualifying programmes in relation to parents with learning difficulties.

Strand 5: User Driven Commissioning



DRUK have been successful in getting agreement for a pan disability group working with Tower Hamlets CCG and Tower Hamlets Local Authority and a change development worker has been recruited. The point of this is for the lived experience team to influence the commissioning cycle for direct payments support, and we will be recording the process of change both from their point of view and that of the local authority. There has been less success with a site involving wheelchair users and CCG's in North Yorkshire. High level professionals within the NHS have been committed to coproduction, in principle; however this has not translated into action by commissioners. We are learning both from success but also from the frustrations of the process.



We are currently discussing the merits of widening the definition of 'User-Driven Commissioning' to include not only commissioning in terms of procurement, but other activities where disabled people have authority over how services are designed and delivered; for example, in the design and delivery of training courses for commissioning bodies.

The research design is based on the principles of 'Appreciative Inquiry', which can challenge institutionalised ways of working, in order to generate alternative practices. To that end, the interviews will capture some of the elements of 'dream' and 'design' which are integral to this methodological approach. Through the interview process, we will encourage participants to formulate their vision of how co-production could influence the future of health and social care.

Lancaster Disability Studies Conference

6th – 8th September 2016, deadline for abstract submission **31st March 2016** (<http://www.lancaster.ac.uk/disabilityconference/>)

We're hoping to put together a panel for this conference. If you have any thoughts/ideas about this or would like to volunteer please speak to Val ASAP.

Articles of Interest

(Click on the titles to view the articles)

- Nicky has written a draft literature review on **Co-Production** and this has

been shared via Basecamp and can also be found on the shared drive for those that can access it (link can be found in email sent 1st March)

- [Kicking The Cat: How patients can help to shift the rule-bound healthcare system](#)
- [Evaluation of Music in Mind](#)
- [Could music projects cut the cost of dementia care?](#)
- [The secret life of a dementia carer: I'll never forget finding an iron in the fridge](#)
- [On Practices, Change, Recruitment, and \(Mis\)Fitting](#)
- [Monitor Risk Assessment Framework \(2015\)](#)

Dates for the Diary

10th March, 4-6pm, **Jenny Morris** Norah Fry Annual Lecture.