



Getting Things Changed

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Newsletter 4

Christmas 2016

HAPPY CHRISTMAS!



We are now just over half way through our three year project, and lots has been happening since the last newsletter in the summer.

Keeping the conversation going



In September we had two days of workshops, as planned, to mark the halfway point of the research. One day was devoted to discussing **problematic practices** and comparing notes across the

strands about what we were finding, and how to interpret the issues faced by disabled people. The second day we ran as a 'co-production' day, where four of the groups helping to co-produce the project were present – the Lived Experience team from Tower Hamlets; the Forget-me-Nots (dementia empowerment group in Swindon); the Misfits (drama group in Bristol); and the disabled students' group from the University of Bristol. All the groups presented something about their own experiences, their issues, how they are taking part in the project, and what they feel is important for us. We learnt a massive amount from them, and not least that: different groups of disabled people can and do support and learn from each other and that co-produced research has a big emotional content to it. Not everyone agrees about what is problematic, and how practices should be changed. That is great, because it's a discussion based on the very diverse lived experiences of all the people involved. This is ongoing work, but really important for the project overall. * See our report of the workshop days, which will be available on our website.



Writing, reporting and disseminating



At the start of September, we ran a panel at the Lancaster Disability Studies conference, which gave each of the strands a great opportunity to pull together some key points about our goals, ongoing research and of course to network with others in the disability and activist communities. The discussion and feedback were really useful for us – for instance, making us think about some of the key themes which are emerging about change across the project.

Since then, we've all been busy continuing our writing on the project, but the main 'external' event has been the Thinking Futures Festival, organised by the ESRC, where the disabled students' group ran a very successful Forum Theatre event. They presented scenarios based on their own experiences in the University of Bristol, and audience members took part by offering suggestions and ways of 'altering the script'

to change what was happening. We are still digesting and discussing how to report on all this, but in the meantime, CONGRATULATIONS to such a great group of students for leading this workshop so effectively.



(<http://www.bristol.ac.uk/fssl/festival/>).

Update from Strands

Strand 1: Getting Good Support.

This is the strand which is collecting video data with people with learning disabilities, as well as people with dementia. We are interested in the micro-analysis of how people are treated, how conversations can be empowering or facilitating, and how disabled people may also get excluded from the talk going on around them – and of course how that can be changed. We have a good set of data now, thanks to Joe Webb's tireless efforts, and we're trying to pause for some analysis. We're particularly



getting interested in the activities which take place in groups of people with dementia, and how these activities work in practice. Celia Kitzinger and Charles Antaki have both spent time with the team, developing our own insights into matters such as humour, jokes, teasing – but also exclusions and the social actions of choice during activities with a support worker.

Both the **Misfits and the Forget-me-Nots groups** have engaged with the videos, bringing their own lived experience to bear. For instance, how do we talk about 'the past' with people with dementia, what response can work best when someone repeats information, and how can a support worker engage nonverbally to make sure that a person feels listened to?



Finally, we have been planning, with Marina Gall, how to include in this strand a focus on music, where new music technologies are providing opportunities for young disabled people to make music together, at the same time as offering a

means of self-expression. **More to come soon here!!**

Strand 2: Changing the Academy.



The student element of Strand 2 has been a hive of activity over the autumn term. A total of six interviews have been carried out by the student researchers with students from both the University of Bristol and elsewhere. The student researchers have also been busy reflecting upon their own experiences at University and are about to enter into a period of Collective Writing workshops to develop this further.

In November the student group organised a highly successful Thinking Futures event, for the ESRC Festival of the Social Sciences, which was attended by members of University staff, students and the wider general public. The event used Forum Theatre to facilitate discussion around the disabling practices currently experienced at University in order to begin reimagining these practices for the future. The event was attended by over forty people and has led to the group being asked to meet with



Professor Nishan Canagarajah, Pro-vice chancellor at UOB for Equality, Diversity and Inclusion. This is a great achievement.

The students have also been busy engaging with the wider University and Student Union campaigns around equality and diversity. Including responding to the call for information about the provision of support from Randstad, the guidance for personal tutors around disabled students and the University Strategy.

The element of Strand 2 which looks at the experience of disabled staff within higher education has also been very busy. A comparison of six Russell Group universities equality and diversity policies has begun in order to get a sense of "good practice" for both disabled staff and students. Richard Pettigrew's work on "Unconscious bias" has provided Sue and Wendy much 'food-for-thought'.

Preparations are underway for initial interviews with key 'players' with the equality and diversity sphere within the UOB. We aim to gain an understanding of the views and experiences of organisational managers, occupational health professionals, the Unions, Estates and Students Union. Their views and experiences will provide a baseline from which to identify the levers for change.

These interviews will be rolled out to the other six Russell Group universities in the New Year.

Strand 3: Reasonable Adjustments



Earlier in the year, Strand 3 focused on gathering the following information: 1) an audit of Care Quality Commission inspection reports to establish how hospitals in England are providing reasonable adjustments for disabled people; 2) a freedom of information request to establish hospital adherence to learning disability care requirements, as highlighted by Monitor (2015); 3) an online survey sent to hospital professionals and Healthwatch representatives in order to better understand their awareness of reasonable adjustments, and how their hospitals are providing adjusted care for disabled people. All three of these stages are nearing completion, and we in the process of writing up the results for further dissemination. These three stages have



helped us better understand how hospitals currently provide reasonable adjustments, and therefore, also helps us highlight where possible changes can be made.

We had a really great response to our call for disabled people to take part in interviews about their experiences of how hospitals have provided reasonable adjustments to suit their needs. We have now interviewed over 20 people, and will have completed 25 interviews in total, with some extra stories to be told via email. Thank you to everyone who has taken part so far!

In addition to our interviews, we have been finalising our plans for our first reasonable adjustments workshop, where we will use what we have learned to encourage hospitals to make changes to their current reasonable adjustments practices. This will be held on Tuesday 28th

March 2017, and is open to health professionals and disabled people. For more information about the event, please see this link:

<https://www.eventbrite.co.uk/e/the-provision-of-reasonable-adjustments-for-disabled-people-by-hospital-services-getting-things-changed-tickets-29356931372>

Finally, we have had a number of group meetings with disabled people (with the

help of Your Say in Bath, and Living Options in Devon) who are interested in developing our project. They have been of great support in shaping our research ideas, such as ensuring any information we disseminate is accessible, as well as ensuring our interviews with disabled people were appropriate. We look forward to continuing this collaboration for the remainder of the project. **Strand 4: Successful Parenting**



Work on Strand 4 has continued – but has mainly been behind the scenes! Our efforts have been focused on gaining access to our chosen sites in order to start exploring the 'successful' cases that have been identified. As a research team, we have not provided a definition of 'success' but have invited key people within different services working with parents with learning difficulties to choose examples of work that they see as 'successful'. We are then using this as the jumping off point for an exploration of social practices affecting this group of parents.



Getting permission to start our inquiries has proved to be immensely time consuming and has at times left us feeling quite confused by the complexity of all the different stages and processes. However, we are now underway!

So what have we learned from this experience? Mainly, it has been important to us to have an insight into this complexity and our own struggles to navigate successfully through it. We wonder about the extent to which our journey as researchers may mirror some of the challenges service users face in finding a path through the variety of agency systems and processes – but more on that when we have more data to discuss! The second learning point for us has been about the processes within the Strand 4 research team, and how we work together as a group, given our very varied professional backgrounds. How do we develop a common language and understanding – and what social practices are we each bringing (usually unconsciously) in to our shared activity? Again, questions that inform our group discussions and to which we will return.

Strand 5: User Driven Commissioning



The Lived Experience Team in Tower Hamlets is now working with the local authority, not just on the re-commissioning of direct payments services, but also on personal health budgets. With Peter Gay, the change development worker there, Bernd and the team are producing some writing about the learning in this site.

Disability Rights UK has also been working on 'Making Disability an Asset', enabling and promoting disabled staff in the NHS. We plan to tease out the positive ways in which disabled people can make a difference, and what helps this to really work and to change bureaucratic structures.

We now have a close connection with Bristol Disability Equality Forum (BDEF), where disabled people have had a great success in changing the policy of Bristol City Council in the re-structuring of money coming from the Independent Living Fund. We want to support BDEF to look at this example, to really flag up what works and to enable more such actions to make a difference. Although there are many



barriers to genuine co-production, which we are interested in, we still want to flag up the importance of change, the ways in which disabled people themselves can make a difference.

Staff news

There have been a few staff changes, with Sheila Trahar retiring (not gone away!) but replaced by Marina Gall from Education, who is bringing an interest in technology and music to the project in Strand 1. We'd like to say a big thank you to Sheila for all her inspiration in Strand 2 with the design of the disabled students' strand. Sue Porter has now taken over leading the whole of Strand 2, 'Changing the Academy', and Wendy Merchant is now also working on the part of that strand which is about disabled staff in HE. Mike Steel has joined the project for one day a week, mainly in Strand 5, and Vicky Mason now has an extra day and has been helping with the very busy activity in interviewing people about their hospital experiences in Strand 3. Welcome to everyone, and thank you for helping to keep such a large and complex show on the road.

Dates for the Diary

Thurs 2nd Feb – Norah Fry Centre for Disability Studies Annual Lecture with Francesca Martinez!

Tickets are free and available from this link.

[https://www.eventbrite.co.uk/e/the-beauty-of-diversity-annual-lecture-tickets29609547955](https://www.eventbrite.co.uk/e/the-beauty-of-diversity-annual-lecture-tickets-29609547955)

Definitely put this date in your calendar!

Tues 28th March – Strand 3's workshop - The Provision of Reasonable Adjustments for Disabled People by Hospital Services.

This is open to everyone and tickets are available from here <https://goo.gl/D6yRFf>

3rd to 5th July - 10th International Critical Management Studies (CMS) Conference 2017 – The team are hoping to submit a paper in the Ableism in management, organizations and employment relations" stream in collaboration with Andrew Sturdy.

