



## Getting Things Changed

**Newsletter**

**July 2016**

Over the period since our last newsletter from the project in February, there have been big changes in the wider world which impact on disabled people. For instance, our exit from the EU will affect disabled people's lives, and this reminds us that the wider political scene has an impact on the social practices which exclude or include disabled people. It is important that we contribute to keeping disability at the top of the agenda, so that disabling barriers are not ignored.

### Keeping the conversation going



Regular 'ideas' meetings, both face-to-face and by Skype, have kept our project team sharing thoughts with each other. We have for instance started to grapple with ideas about co-production and equity in research; and about how we can understand the complexity of social practices – what excludes one person

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might very well include another. All these discussions continue, but in the meantime, Vicky Mason has moved forward with discussions with self-advocacy groups about what matters to them. Their biggest theme so far was that for change to happen their voices need to be heard, not just with those in power i.e. via commissioning services, but by working with engineers and designers of facilities etc. to make them see the world differently. We will talk soon with our advisory group on July 26<sup>th</sup> about how to take some of these central messages forward.

### Writing and reporting our outcomes



The outputs we mentioned in our last newsletter were reported to the ESRC via the 'Research Fish' in March. Since then, we have continued with our blog pieces (<https://gettingthingschanged.wordpress.com/>) we are keeping an impact log on a monthly basis, and also started to write articles and to form our ideas into conference presentations. We have a panel accepted at the Lancaster Disability



Studies conference in September 2016 (<http://www.lancaster.ac.uk/disabilityconference/>), and it's great that the proposal was led by the Research Associate group, particularly Stuart Read. We are pursuing papers about the turn towards social practice, findings about reasonable adjustments in Health, co-production in making change happen, practices that exclude people with dementia, and the ways in which people with learning disabilities are included in social work training.

Last but not least, the group of co-researchers in the 'Disabled Students' part of Strand 2 have been extremely active! Big congratulations to them on making a successful application to the ESRC Thinking Futures festival in November where they will be leading a workshop using Forum Theatre methods on November 7<sup>th</sup> in Bristol (<http://www.bristol.ac.uk/fssl/festival/>).

### **Update from Strands**

#### **Strand 1: Getting Good Support.**



It's been a very busy time in Strand 1 over this period, and we have a reasonable amount of data collected now, as well as many routes into further participation (largely thanks to the persistence and enthusiasm of our RA, Joe Webb!)

We have recruitment videos produced by our co-production groups, the Misfits (for people with learning disabilities) and the Forget-me-Nots (for people with dementia). Both groups have been very active in offering their insights about communication. We also have four sets of video data from people with learning disabilities and their PAs, and a growing set of videos mainly from group situations with people with dementia. So our settings range from home to community, shops, crazy golf courses, greenhouse, doing crosswords, and even inside a minibus. The strategy of going back to participants to share and discuss data has been very useful so far. So, we're interested here in the 'micro' things that happen in communication, for instance:

- What does a joke do, and on whose terms?
- How can the conversation be led by the person with dementia?
- What does it take to facilitate someone to be 'in control'?

We're really looking forward to discussing some of the data further with our two



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consultants, Charles Antaki and Celia Kitzinger.

## Strand 2: Changing the Academy.



Sheila Trahar's concept of how this strand would work has more than proved itself to be successful! The group of disabled students, supported now by several RAs, but led by Vicky Mason, have been incredibly active. See above for the students' success in the ESRC Thinking Futures Festival! The group is a model for all of us in the project, having set up their own 'Basecamp' site, with a continuous stream of ideas and communication with each other. As we go into the summer months the group are embarking on the data collection phase of the strand, recording their own experiences of student life as well as developing their data collection tools for engaging other students in their work. The group are certainly going to be a fantastic contributors to our project, and we are all looking forward to working further with them over the course of the project.

## Strand 3: Reasonable Adjustments



Strand 3 (Reasonably Adjusting Health Services): This strand is currently working on three pieces of research. First, an audit of hospital inspection reports from the Care Quality Commission published in 2015 to establish current provisions of reasonable adjustments. This audit is now completed, and Stuart is in the process of finalising an academic paper describing the findings. Second, an online survey for both Healthwatch representatives and hospital professionals interested with patient experience about their experience with reasonable adjustments in hospitals. The survey period has now ended, and the results are being developed as a draft paper. Third is the freedom of information request which was submitted in order to assess hospital trusts' compliance with the Monitor criteria regarding care for people with learning disabilities. The majority of responses have now been received, and we hope to write an academic paper



shortly. In the next few months, we will begin to complete interviews with disabled people regarding their experiences of reasonable adjustments when accessing hospital care.

#### **Strand 4: Successful Parenting**



Our long, and slow, journey through the NHS ethical approval process is getting close to the end. We have been granted a favourable opinion by the Research Ethics Committee and are awaiting the opinion of the Health Research Authority.

We have had discussions with 3 sites who have referred themselves as examples of multi-agency "successful practice" when working with parents who have learning difficulties. These sites were identified by professionals who are members of the "Working Together with Parents Network" - a free resource supporting some 700 professional members who work with parents with learning difficulties.

In trying to identify areas of 'successful' practice it has become clear that there is neither a standard way of working with

parents who have learning difficulties nor of organizing the services that do exist. For example; one potential site is an NHS organisation and the Learning Disability Parenting Team (LDPT) is 'owned' by them. The LDPT was set up in response to the large numbers of parents with LD whose 'cases' ended up in court under child protection proceedings. This service sits within 'health' and works closely with the local authority social care teams. Our second potential site has a service for parents with LD run by a small team of Occupational Therapists. In contrast to the first site, this sits within an integrated health and social care partnership but is 'owned' by social care. We encountered a different organisational approach when I contacted a site local to the University. Initially, they struggled to understand the concept of a parent who had a LD and what services they would need. They suggested that a few years previously they had operated as an integrated NHS and social care team but had now reverted to only social care.

The difficulties we have experienced as a team of four researchers with different professional backgrounds trying to obtain information about services available in different geographical areas has been time consuming and challenging. It has been difficult to identify services aimed at parents with LD as each



area is different; some having specific services which could be located in either health or social care organisations while some have no services at all . The 'local' nature of the services means that the specific services we have identified are often 'buried' within a sector of service provision that wouldn't initially suggest it housed a service for parents with LD. For example, one site housed its service for parents with a LD within a mental health organisation. Whether parents who have LD can easily establish firstly, where relevant services are and secondly, easily gain access is questionable.

### **Strand 5: User Driven Commissioning**



Co-production in itself can be seen as central to change. Tackling the bureaucratic processes which characterise social and health care, disabled people themselves can be the leaders of change. This strand is interested both in stimulating change across different sites, and also capturing the 'vision' and understanding how co-production can make change happen.

Since our last newsletter, we have set up a Lived Experience Team of disabled people working with Tower Hamlets Local Authority, co-commissioning the Direct Payments Support Service. The Lived Experience Team have developed a set of 'Invitation to Tender Questions' – following this adjustments to the service spec are being made. The LE team has gained agreement from Tower Hamlets' officials that they will co-assess the bids and have a 20% stake in the final contract award, and the tender is to go live in August. Managers at Tower Hamlets LA are already looking at ways of making the User Driven Commissioning sessions and outcomes sustainable, potentially adopting the model in other care areas.

A small team of experienced disabled people has been put together to assess the extent to which bids for workshops at the 'Pop UP University' of NHS England Health and Care Innovation EXPO 2016 have been patient-led. Scores were complemented by recommendations for improvements and mutual benefits. It is now for the Strand 5 team to explore the impact of these assessments, by exploring further versions of the bids, talking to bidders and NHSE (if applicable) and observing actual delivery at EXPO itself. A number of attempts have been made with further sites, eg with an Inclusion Health group sharing the starkest



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inequalities, but plans still need to be finalised.

Difficulties in recruiting further sites has meant that we have softened our criteria and now focus on service delivery more widely (not requiring a fully fledged procurement exercise under commissioning) – as long as there is scope for disabled people to substantially shape agreed changes in service delivery and models.

In terms of research we are increasing our understanding of commissioning as a social practice, specifically with regards to the barriers in recruiting sites and starting informal negotiations about commitments from statutory decision-makers. There are legislative, political and logistical forces which may or may not influence the bureaucratic and everyday habits of professionals. Equally, there may be engagement skills and experience lacking in professionals used to manage contracts for decades without ever involving people with lived experience. . This approach not only increases our academic understanding of disabling practices but also provides us with a firm basis on which to challenge and change practices so that they are more inclusive of disabled people and services deliver outcomes which matter to people.

We now have a much greater understanding of what commissioning staff perceive to be the challenges and risks of co-commissioning services. Using this understanding we have designed a set of scenarios aimed at provoking commissioning and procurement leads to think about perceived risks differently. Our intention is for staff from commissioning organisations to work through these scenarios and develop an alternative practice of commissioning that places coproduction at the centre of the process. This all needs to be tied in with a coherent research plan.

### **Staff news**

With such a large team in this project, it is inevitable that we will be saying goodbye to some and hello to others. We have to report therefore that we are losing **Sheila Trahar** due to her retirement. Sheila will continue to take part in events until Christmas. We would like to thank her for her great contributions to this project, and wish her well. We are also losing **Alan Roulstone** from the wider team, who has made tremendous impact within Disability Studies in the UK, and we also wish him well in a new, quieter life! **Sue Porter** will expand her role to include the strand leadership of Strand 2 as a whole.



## Dates for the Diary

**26<sup>th</sup> July** Advisory Group (Focus on Strands 1 and 4): NCVO, London. Advisory Group members will be attending a one day meeting where we will be asking for advice on Getting Good Support and Successful Parenting.

**6<sup>th</sup>- 8<sup>th</sup> September** Lancaster Disability Studies Conference: Panel about Change presented by RA group.

**7<sup>th</sup> – 8<sup>th</sup> September:** Innovation EXPO 2016 conference in Manchester

**19<sup>th</sup> and 20<sup>th</sup> September:** Cross-project workshops in Bristol. Day 1: Co-production theme; Day 2: sharing and discussing findings from strands relating to social practices and change.

**7<sup>th</sup> November:** ESRC Thinking Futures Festival: Student co-research group at Watershed, Bristol.