Getting Things Changed

Co-production Day: September 20th 2016

The Forget-me-Nots from Swindon, the Misfits from Bristol, Disabled Students' Research Group and the Lived Experience Team from Tower Hamlets.

Thank you for joining the Getting Things Changed Team today, and for helping us think about lots of things.

We were talking with our group about the label 'disability'. Some of us in the group are happy with that label, while others aren't. For me, I'm happy to label myself as disabled, because considering myself disabled means that I've got access to all sorts of people. And it's been very important today to see that we all have shared experiences, whatever our disability (Laurine from the Students' Research Group).

Reminder of whole project

We want to find out....

- What is going wrong for disabled people?
- How can we understand how things work – the small and the big issues?
- What are disabled people's own solutions?
- How can things change?
- What needs to be done to get things changed (by policy, practice, by disabled people themselves....)?

You can open the rest of our first presentation here:

Bernd Sass from DRUK: USER-DRIVEN COMMISSIONING

The idea of this strand is that we go directly to people with lived experience, and seek to influence what services and supports look like. There are several sites involved. We try to work with whoever wants to work with us. And we want disabled people to run the show! It's an interesting starting point, because it's very open at the beginning.

There are several projects based in the NHS, which look to people who are disabled, who are already working in the NHS. They might be nurses, doctors, but also porters, receptionists. It's looking to those people to make change from within that massive organisation called the NHS – which we all know and most of us love dearly! We look to them to become our partners, to improve the NHS from within.

Lived Experience Team in Tower Hamlets

Tim: I get a direct payment every month; it’s to help me get out, to play tennis. And I feel very privileged to have that. So when I got the opportunity to help Peter with the project, I thought it would be a good way of giving something back. I’m just one of the group – there are other people involved as well.

Peter: A really important part of this work has been talking through people’s experience of support. People have said: I want them to listen to me, I want them to offer me information in a way that I can understand. And to offer me help in places that are good for me.

An unreconstructed council meeting is transformed into

A productive partnership

Very simple things, but it’s realising that Tim and the rest of the team are the experts. And they can get the confidence to change things within the Council –that’s the important journey that we’ve been making. Through what you know, you can go and change something. People buying these support services need your expertise to do it properly.

Nadine's message to others who want to change things:

1) **Get past the Big Brick Wall of the NHS or the council. There'll be one brick in the wall that will shift, and that may be just one person. You've got to find the right person who says: 'Yeah, we can do that'.**

2) **Tell the council: 'We're doing it for you'. This is what's in it for you – we are here to help!**

The Disabled Students' Research Group

For me, participating in the project is about trying to change things. But also just to feel that sense of belonging, when society's trying to tell you that you're a second class citizen. When we pull together, we're really strong.

'I know equality of opportunity is highlighted, but I felt labelled as soon as I went to Disability Services. You're forever having to prove things, with medical letters and so on. The reason I'm in the project is to try and highlight some of the issues that I've experienced. Hopefully it will bring up changes that will help other students in the future, and support their learning.'

'I think it's important that we don't all sit in cubicles, ticking boxes on computer screens, which stop us communicating with each other'

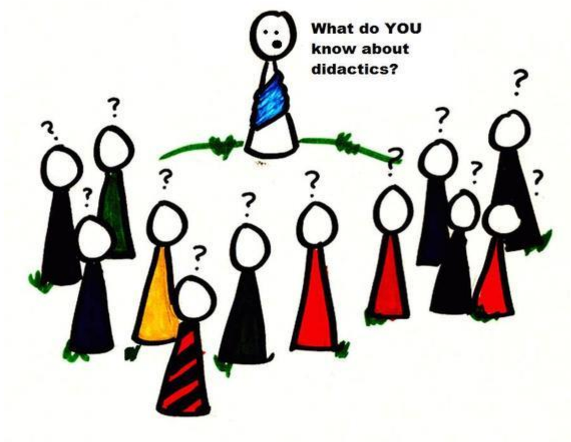
'They gave me extra time and everything, and that was supposed to make everything fine, but actually it was still difficult. So I was left thinking, maybe this is not for me. But actually I do want to study. It can all make you feel 'It's my fault, because everyone else is just getting on with it'.

What is it like taking part in research?

And the weird paradox of this research project, is that we're now doing an academic research project about *why* we find it difficult to engage in academia.

The reason we want to get involved in this project is also the reason that sometimes we can't get involved, because of our disabilities, when we can't do all the things that we want.

Part of the thing about being a researcher in this project is good – we're hearing more about how things are done in practice.
In a University, a lot of things are just done in theory – that's their speciality!



'Getting Good Support' (Strand 1) is working with two co-production groups. First up, the Misfits

The Misfits showed us a video from the project. It showed a young man going shopping. But he was stopped from getting what he wanted in the shop.

These are some of the things the Misfits said, when they acted out the scene:

'They did try to persuade him, they pointed to things in the shop. I think that the young man can have what he wants. Then the next day the PA can have what they want for him.'

But it's his choice – he's going to the shop to buy himself a treat, so it's his choice. The support shouldn't tell him what to do.

How could it have been done differently?

***D:	What do you want, a cake?***
***K:	Yeah***
***D:	but you just want one don't you? And that's like a whole bunch of them.***
***M	How about you buy them and eat just one now? Then you can have what you want. It's your life.***

We talked about this a lot: If you had a PA would you want them to advise you, maybe say to you not to buy the buns you want?

Kate and Paul: Yes. I'd choose fruit and yoghourts. It's much healthier.

Sandie from the Forget-me-Nots summed up:
As someone who has seen that happen, I think that person should have had freedom of choice. Just because he was buying a four-pack of donuts, that doesn't mean he's going to eat the four pack. Most people are generous, and say, would anyone else like one? OR put them away for another day. I would go spare, because those people led that man to the choice they wanted. And that man then lost his freedom of choice. I feel very strongly about that.

Last but not least here are some of the points from the **Forget-me-Nots from Swindon.** Their presentation was: **Don't panic – life's not over yet!**

My family and friends had been concerned about me becoming withdrawn. I've never been one for going to the doctor, but eventually I went, and he thought it might have been depression – and he got me on a bunch of happy pills.

I wanted to ask somebody about my diagnosis, but there was nobody about. And I had my independence taken away from me – all at once. I felt like a prisoner.

Sandie: You were told: ‘You’ve got dementia, there’s the door’. And that’s how you are left. You watch the TV, and see dementia patients, and think: ‘That’s not me’. Because you see dementia patients sitting in a chair, doing nothing.

Roy: These two and the others – we all suffer from the same thing more or less, dementia. And we understand each other. Whereas out in the general population, they don’t understand you. The only people who know what we’re going through is us.

Harry: They give you forms to fill out, but they don’t explain anything. Personally, the first one they gave me, I screwed up and threw it away. They wanted too much information from me, and I thought why should I give this to you?

Sandie: But look at us now. We go to the Forget-me-Nots, we fight for our rights, and I think we’ve got a wonderful life. And I hope we can carry on like this for ever.

Forget—me-Not, it’s not a community. It’s just a house, that’s got art rooms and everything in it. It was actually somebody’s home. It belongs to the NHS, but we are the only one in the area. We keep on saying,

***Do they not realise that the more Forget-me-Nots they have,* the more people would stay out of care homes. And it's cheaper – we're dead cheap (Roy: 'Speak for yourself!')**

Finally, how did it go today?

Thank to you everyone who filled in evaluation sheets!

👍

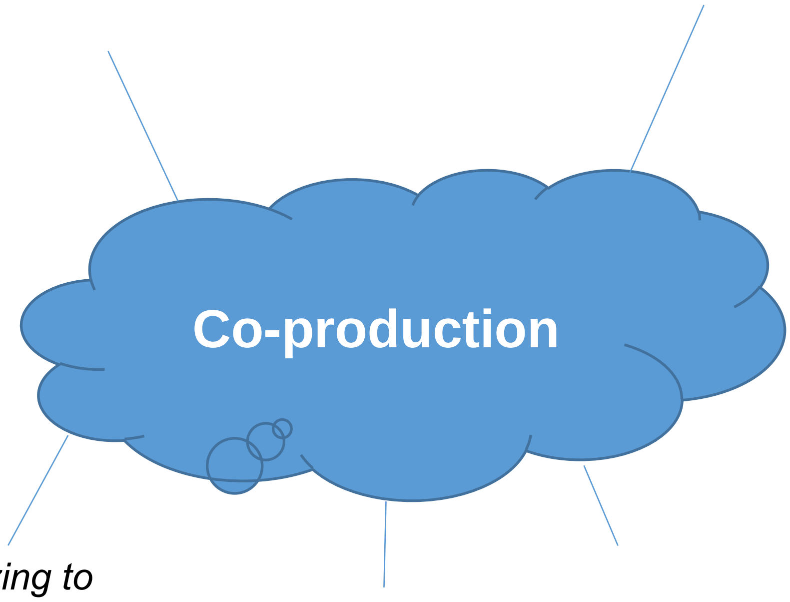
- Meeting lots of new people who are so keen to change the world
- We offer people – being involved. Getting my point and my views across.
- Great learning about diverse strands of the project
- Lots of different perspectives
- Creative, challenging, informative – lovely atmosphere too!
- I liked learning about how people get good support

👎

- It was too hot
- It was too cold (honest!) It was definitely too small a space!
- Some bits were complicated to understand.
- Two people felt they were ignored at times, or talked over.

What is co-production? What have we learnt today?

GROUP 1



Vocalize and strategize

Team work

It's amazing to work together

If you're silent, nothing is going to change

Everyone's got a voice, everyone has opinions, and people need to hear it!

GROUP 2

Co-production: We can all learn something. We all have different roles, but they're all valid.
Co-production can find a solution!
Coproduction can produce a lot of ideas. And it can be fun.
Coproduced film and Paramount Studios?!
Coproduction means different things to different people.

FROM US ALL

Co-production needs good communication – sharing perspectives.

There's a lot of emotional labour too: we need to make sure our methods reflect that. **Thank you to everyone!!**