



### How can we best understand the barriers which disabled people still face in the UK today?

#### Summary

- Disabled people are often disadvantaged or excluded because people tend to do things in ways that are shaped for non-disabled people.
- In our research, we have been finding out about these problems, and particularly what lies behind them. We are working on five topic areas, 1) 'Frontline' support practices; 2) Practices in the University itself; 3) Reasonable adjustments in Health Care; 4) Support for parents with learning difficulties; 5) User-driven commissioning.



Problematic barriers can be so hidden and evasive you can hardly make them out. (Bernd Sass, Disability Rights UK)

Many of these barriers are not about overt hostility to disabled people. They are hard to see, because they are built into the things we take for granted in the way we do things. Our project is questioning these assumptions.

- The issues we are seeing can be divided into three interconnected themes.
  - 1) The self-identification (or self-declaration) of people who are disabled;
  - 2) Interactions which are shaped so that they exclude disabled people;
  - 3) The attitudes of "professionals".
  - Who is disabled? Identification and self-identification are important, so that reasonable adjustment can be made. Disabled people have rights for instance in health and social care, but they can only be put in place if service users identify themselves or self-declare as 'disabled'.
  - Practices which should be 'open' to everyone are often shaped so that they favour non-disabled people. We can see that at the micro level, in interactions between professional practitioners and disabled people.
  - Many of the barriers are about attitudes towards disabled people. Disabled people are seen as posing a problem, for instance when they study or teach in universities.

## Who is disabled?

Knowing who counts as disabled is a current issue in the UK<sup>1</sup>. Our research is showing that the identification and self-declaration of disability can be missing. For instance, we have found many examples in health services of inconsistent use of flagging of patients with “learning disabilities”, which then leads to a lack of reasonable adjustments to meet their needs in primary or secondary care<sup>2</sup>. For instance, adjustments to communications are identified as barriers by patients with learning disabilities and their families<sup>3</sup>. Once in hospital, people have told us that there is a lack of communication between departments, which means that patients are having to tell their information over and over again to staff.

In another strand of our project, we are starting to look at what makes ‘success’ in services to support parents with learning difficulties<sup>4</sup>. The services that support parents with learning difficulties appear to allocate many of their resources to the identification of a learning need in parents. It is only after this has been identified that interventions can be adapted to the needs of the parents with a learning difficulty. We know also that in order to get these services, professionals need to understand that equal treatment of all parents can lead to discrimination against disabled parents. For instance, some standard parenting programmes for ‘vulnerable mothers’ only begin at the third month of pregnancy. However, court care proceedings are supposed to be concluded within 26 weeks<sup>5</sup>, providing a very tight time frame for these parents to demonstrate and to improve their skills.

Despite these needs for self-identification, not everyone who might qualify for reasonable adjustments or for specialist services sees themselves as ‘disabled’; not everyone has an understanding of the positive ways in which a disability identity can be an asset, and a force for change. User-driven processes and co-production for instance frequently do not include ‘all’ disabled people, and we have found that there are many barriers which stop people from ‘declaring a disability’ in employment.

## Excluding people through interactions

In our research about frontline support practices, we are working in co-production with people with dementia. Conversations with people with dementia are really important, as it has been shown how ordinary social talk is a way of enabling people with dementia to live

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<sup>1</sup> Roulstone, A. (2015) ‘Personal independence payments, welfare reform and the shrinking disability category’ *Disability & Society*, 30 (5): 673-88.

<sup>2</sup> Heslop, P., Blair, P., Fleming, P. et al. (2013) ‘Confidential Inquiry into Premature Deaths of People with Learning Disabilities’ p63-64 and 109-10. <http://www.bristol.ac.uk/media-library/sites/cipold/migrated/documents/fullfinalreport.pdf>

<sup>3</sup> Ali, A., Scior, K., Ratti, V., (2013) ‘Discrimination and Other Barriers to Accessing Health Care’ *PLOS One* <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3741324/>

<sup>4</sup> Tarleton, EJ & Porter, SM, 2012, ‘Crossing no man's land: a specialist support service for parents with learning disabilities’. *Child and Family Social Work*, vol 17., pp. 233

<sup>5</sup> s.32 (1)(a) Children Act 1989 as amended by s.14 (2) Children and Families Act 2014

well<sup>6</sup>. But sometimes the way ‘ordinary social talk’ works can become problematic, and people with dementia themselves have picked out the following issues. For instance, another person might ask a probing question which creates demands on the person’s memory. We have examples where someone asks: ‘what did you have for lunch? Can you remember?’ or ‘do you remember what we did last week?’ Direct questions about the distant past can also create problems, suddenly creating a feeling of incompetence. Another issue picked out of our data by people with dementia is the problem of getting into conversations; we have seen how they find themselves in situations where it is hard to talk to each other. Therefore everything gets directed towards the staff member or non-disabled person in the group.

We are also recording conversations with people with learning disabilities, in interaction with their personal assistants. Some of the issues they have identified as problematic are about how to ‘manage choice’, while at the same time advising and guiding the person with learning disabilities. We have examples where shopping can become very confusing, due partly to the large number of choices in a supermarket; when the PA says: ‘This is expensive’, then the person can lose confidence about making a correct choice for themselves.

### Examples of problems in attitudes: the elephant in the room



"The elephant in the room" is rarely something cute (as in this picture!) For instance, we saw an online discussion between lawyers about a recent case involving parents with learning difficulties<sup>7</sup>. The discussion began with the comment "Isn't the elephant in the room the fact that we are now at a stage where it is considered desirable for folks with substantial learning difficulties to be parents in the first place...? And who has to pick up the tab when said parents are unable to care/bring up their children properly?" This is an example of the kind of attitudes routinely faced by parents with learning difficulties.

In other parts of our research, we have seen how negative attitudes can become entrenched, and are very difficult to perceive. For instance, our work to ‘change the academy’ came up against a decision to charge disabled staff at the university for car parking. When challenged on this, the argument was that ‘all staff have to pay, so why not disabled staff?’ (see also <sup>8</sup> in hospital car parks). The wider picture of what disability means, and the costs of managing working life as a disabled person, are not well understood – ‘justifications’ for disabling practice can reveal some of this lack of comprehension.

The way language can be used to justify discrimination reveals some of the backdrop of attitudes that often remain hidden. Disabled students for instance receive the message that they themselves constitute ‘the problem’, and that the university may be doing what it can to accommodate them. Similarly, we have seen elsewhere how professional practice clings to the moral high ground. ‘Co-production’ in the NHS can become part of the discourse of

<sup>6</sup> ‘Communicating and Language’ [https://www.alzheimers.org.uk/info/20064/symptoms/90/communicating\\_and\\_language](https://www.alzheimers.org.uk/info/20064/symptoms/90/communicating_and_language)

<sup>7</sup> <https://www.lawgazette.co.uk/law/solicitor-warning-over-legal-aid-disputes/5045939.article>

<sup>8</sup> <http://www.bbc.co.uk/news/health-20628873>

professionals, but we have seen how it fails to move beyond words, into real action to engage with disabled people.

## Getting Things Changed

Some of the barriers and problems we have found in our research are well known. Others are more subtle. Analysing the problems is however only a first step towards change.

- At the micro level, simply watching and discussing video data with participants can help people to see what needs to be adjusted, or how they could do things differently. We can also turn round ‘unsuccessful practices’, and work out through role-plays what might be better. That is what we are doing with our co-production groups.
- Disabled staff and students at the university are taking direct action to make sure they have a voice and can make sustainable change within university structures. Similarly, peer modelling by disabled NHS staff has enormous potential if supported by the executive.
- Workshops built on successful practices will enable to work out how to shift and adjust what they are doing to fit disabled people’s needs.
- Changes are being implemented via disabled people themselves, via user-driven commissioning. We have examples of service specs for tenders that have been entirely written by disabled people using the service concerned.

## Key questions

1. How do people know if they are disabled and does it matter if they self-declare? For instance, if anticipatory reasonable adjustments were made more often, as legally required, perhaps fewer people would need to be ‘identified’ as disabled.
2. How can interactions be turned around, so that disabled people are better ‘included’ in social life and in making their own decisions?
3. We all need to learn about what we do ‘unconsciously’ that discriminates against disabled people. Can that help us to make changes in our own practices?



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