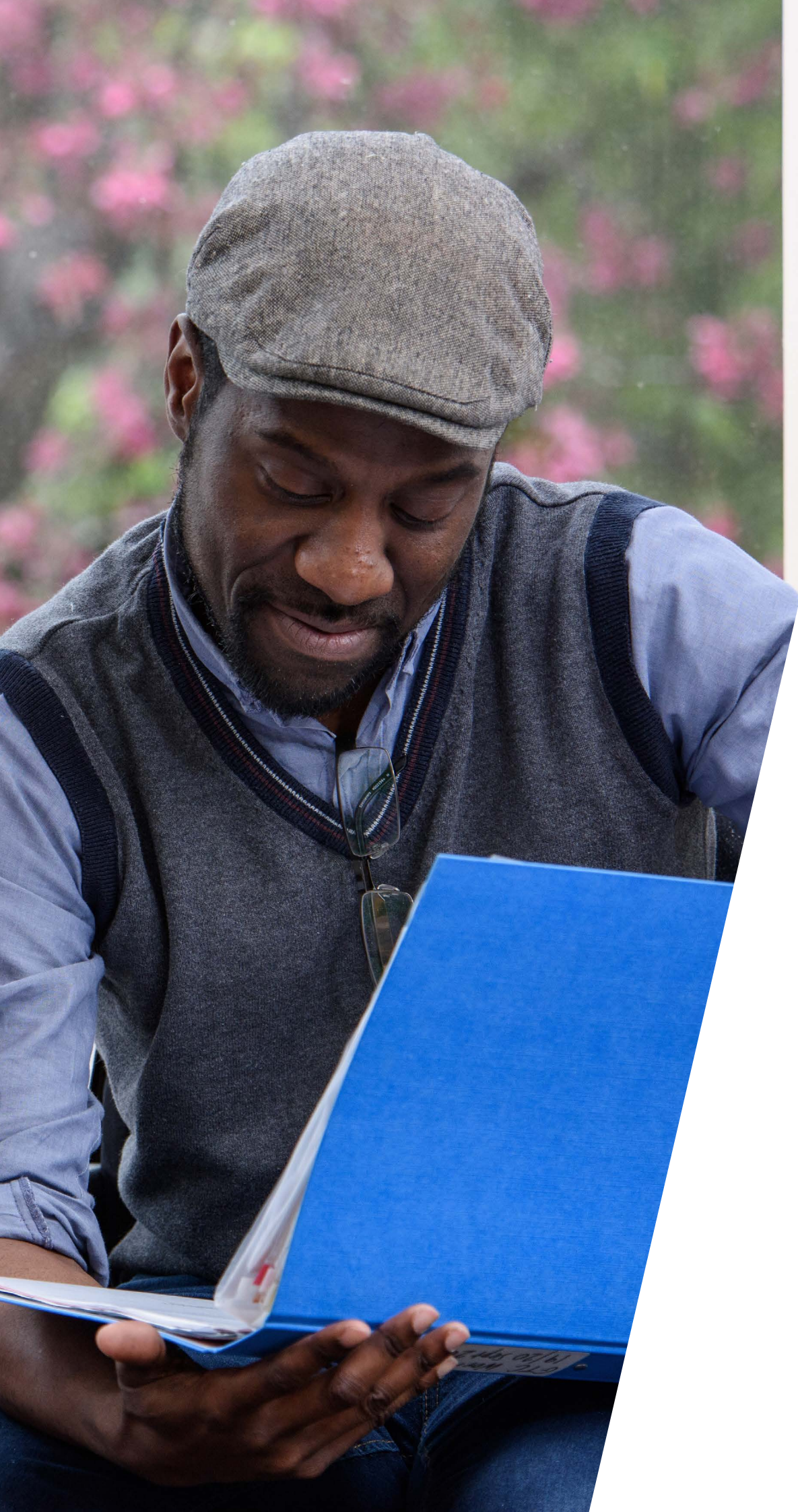


# Getting Things Changed

## Summary of full report





# Summary

## The research

- ‘Getting Things Changed’ was a large multi-centre programme of UK based research in Disability Studies, funded by the Economic and Social Research Council between 2015-2018. It was led by a team at the University of Bristol, with Disability Rights UK, the National Development Team for Inclusion and partners in three other universities.
- The research was fuelled by concerns that policy and law do not always translate into practice. The research demonstrated in specific detail that disabling barriers have not been fully overcome by the Equality Act 2010, for instance in public institutions such as hospitals or universities. It was found that policy and practice guidance such as that provided for the Mental Capacity Act 2005 becomes re-shaped by everyday life.
- The scope of the research was wide, covering different contexts including interactions with a personal assistant, groups for people with dementia, music education in special schools, TV and media, hospital care, parenting support for parents with ‘learning difficulties’ and co-commissioning carried out by disabled people’s organisations. We wished to avoid the trap of ‘othering’ practitioners in any of these settings, and so we also conducted research within the university, to put our own practices in the spotlight.
- The methodology used was diverse, and largely qualitative, collecting data including auto-ethnography and videos of naturally occurring interactions to written surveys and interviews. 203 practitioners and 245 disabled people took part in the research, with impairments ranging from physical, sensory, mental health issues, autism, learning disabilities and dementia, and many multiple or complex impairments. In this report, we have used the term ‘parents with learning difficulties’ because these were people who did not have a formal diagnosis. Elsewhere, we have used the term ‘learning disabilities’. The term ‘disabled people’ is meant to encompass anyone who faces social barriers because of an impairment.
- The research was co-produced with disabled people and their organisations, especially with Disability

Rights UK. Their viewpoints and input were central both to the research design and to our findings. Half of the core project team identified as disabled people, and drew on their lived experience in the research. Additionally, 18 disabled people took part in three co-research groups across the project, and others were involved in advisory groups or direct action within the work led by Disability Rights UK.

## The barriers facing disabled people in the UK

- Disabled people in this research with a wide range of impairments were facing exclusions, both from the activities of everyday life and within health and social care services. For instance, disabled people who needed hospital care could find that hospitals delivered care or gave information in routine ways which did not account for their particular needs, and people with dementia were excluded from everyday conversations when others used questions which tested their memory.
- Despite verbal adherence to the ‘social model of disability’, many institutions still saw a disabled person as a ‘problem’ to be solved. For instance, disabled students in university found themselves singled out and supported, but ‘different’ from the norm. Some local authorities also slipped into this individual way of seeing disability, questioning whether those in disabled people’s organisations could really represent other disabled people in co-commissioning services.
- Institutional ways of doing things sometimes became stuck, with power differentials, where experts, professionals or managers made the rules. This was seen in the TV industry, but also in hospitals, universities and in social care. Unwittingly, these practices could exclude disabled people, who needed better forms of information, more time, and more equalising ways of communicating.
- This study found that ‘co-production’ could become meaningless rhetoric, a box-ticking exercise in local authorities or hospital care. Co-production worked best where there were genuine shared projects and goals, and where those in authority could learn from disabled people’s organisations on their own territory. Disabled people, including those with dementia, also needed to build their confidence and awareness of their rights.

- Amongst our participants, very few were in paid employment. People with dementia for instance had lost their main source of income following diagnosis, and many participants were contending with increasing poverty.
- Disabled people faced extra labour at every level. That included managing their assessments, provision and interactions concerning support services such as personal assistants, or for those in work, the government Access to Work system.
- Disability was often associated with the 'lay' person, the student in a university or the patient in hospital. It was even harder therefore for disabled staff to feel valued or supported in these institutions.
- Identifying disabled people was sometimes considered to be difficult in mainstream institutions, and in many of the contexts we explored, disabled people did not readily self-identify. It often seemed both to disabled people and others that disability was a negative category in universities, on TV, or even in hospitals.

## A focus on social practices

- Social practices are what people do, which includes all the everyday things we do in our lives, but also professional practices that might impact on disabled people. Our central goal was to understand and unravel disabling social practices, and we attempted this in different ways, sometimes focusing on the detail and at other points considering the wider shape of social practices.
- It was fruitful to see how interactions happened at a detailed level. We used a method called Conversation Analysis, which helped to show how communication practices work. That made it possible to analyse practices to see how interactions evolved on a turn-by-turn basis to exclude or include disabled participants.
- It was not always possible or useful to separate the small things in conversation from the wider things in society. Interaction took place within wider tasks, contexts or constraints and thus could be seen as part of social practices. Conversely, a key to many wider social practices is the interaction which takes place within it. The research found that contemporary social practice theories were very helpful in most parts of our project.

## The positive picture of change

- All social practices gradually evolve and change, by shifts in material resources, competences of the people who carry out the practice, or in the meaning and value attached to that practice. Interaction patterns also change, for instance with mobile phones or social media. We saw how universities have changed practices, with students receiving timetable information on a mobile app.
- Practices can also be re-envisioned and changed more purposefully so that they include more people. We observed how this could happen via technology in music making with the *Open Orchestras* approach, and for people with learning disabilities who have good supporters and personal assistance. A shift in values could also change practice, as in successful support for parents with learning difficulties.
- Analysis of interaction at a fine-grained level could create change, but this tended to be limited to the practitioners who took part in training. We experimented with producing video training materials with people with dementia, based on our research, which will have a wider currency for the future. Changing the shape of practices needed a holistic approach.
- There were common themes to successful change. These included flexibility around the individual person, informality in setting and interaction, professionals who demonstrated humanity and communicated on a basis of equality, and above all support for the autonomy of all disabled people. All those themes were just as important in supporting parents with learning difficulties as they were for people with dementia, or for those engaging in co-production with their local authority.
- Pioneers in services such as hospitals or parenting support often led the way towards changing the competence and skills of others. However, it was easy for that to stop when they moved on. In order for them to have more power to make changes, they needed to operate at a more strategic level, in order to influence and re-shape practices. That happened in the creation of more empowering dementia services via a network and also for instance in the re-shaping of music making by *Open Orchestras*.

- In order to effect change, there was a need to analyse the connections between different practices. Policy and practice often operated in silos, which were uncoordinated. Yet disabled people experience the effects of this lack of connection on a daily basis. For instance, Access to Work systems created extra labour for disabled academics; transport systems needed to be better coordinated with hospital practices or with work settings.

## What are disabled people's own solutions?

- Disabled people bring unique contributions to social life. For instance, the performances of actors with learning disabilities could be differently constructed and more spontaneous than those which were pre-scripted and learnt. People with dementia could help others to slow down and live for the moment, valuing interpersonal friendship and fun. Disabled staff and students in universities brought a new lens to academic endeavour. To become more inclusive, society needs above all to value the contributions of disabled people.
- Disabled people could be catalysts for change, by reframing issues from a disability viewpoint. This happened in the university, but also in co-production with young disabled champions in local authorities. Our much valued colleague Sue Porter used to call that 'Lighting Small Fires'.
- For disabled people, interaction and the detail of everyday life mattered, since they experienced exclusions on a daily basis. They wished to train practitioners, where their input could be powerful.
- Peer support and collective voice were minimum requirements for co-production. It was also considered vital to have a forum for disabled staff and students in universities, where disability was not always currently seen as an asset.
- Co-production was essential, but not always sufficient, for change to occur. It was also necessary to have good allies, and for people in positions of power to listen, interact and learn to be flexible and shift the practices which they took for granted.

## Cross Project Recommendations

- Each branch of 'Getting Things Changed' speaks to different practitioners and policy makers. The recommendations springing from the various strands of our research are set out in the eight Policy Briefings published by Policy Bristol.

## Senior policy makers, strategic managers, commissioners

- Reasonable adjustments under the Equality Act 2010 must be put in place, and all public institutions must have systems, preferably led by disabled people, to monitor and report on how they are adhering to the Equality Act.
- This minimum legal requirement is however not enough to create a more inclusive society. For that to happen, policy makers need to consider how practices are shaped in their institutions, and to carry out a creative re-visioning of practices.
- The Social Model of Disability, even after thirty years, should be the basis of training and disability awareness. That does not mean it can be simply 'put into place', but that it provides a starting point for re-focusing the argument towards practices which fail to include disabled people.
- Senior managers, local council officials and government should consider how disability is represented in their own ranks, and ensure that promotion and recruitment practices are in place which will attract and value senior disabled staff.
- All strategic managers need to put in place a culture of openness about disability, which would include monitoring of physical access as well as signage, images and identification of disability.
- Above all, disability needs to be valued as part of increasing diversity within organisations, and to be seen as a way of promoting better ways of doing things.

## Practitioners, staff, personal assistants, volunteers

- All those who come into direct contact with disabled people need to interact on a basis of equality and sharing, recognising disability as a part of human experience.
- Trust and valuing are at the basis of successful practices, where everyone really believes that disabled people can achieve their goals.
- Informal, more relaxed settings are often the key to better practices, for instance in personal support but also at universities, within hospital waiting rooms, or in dementia groups.
- Practitioners should work with disabled people to create better ways of doing things which draw on their insights.
- Disabled people's organisations need to continue to develop awareness of rights, and to use the law, at individual and collective level, to achieve disability rights.
- Disabled people should aim high, at university, in TV and in every sphere of life. At senior level, disabled people have more power to make changes to practices.
- Disabled artists and performers can help society see the world in a new way. Practices should not be taken for granted, and disabled people can help others to see things afresh and make changes.

## Disabled people

- Disabled people should not feel that they have to make all the headway on change for themselves. They can become stronger by forming a collective voice.
- Identification as 'disabled' should be considered a positive.

'Getting Things Changed' took place at a time of increasing service cuts and oppression of disabled people. While it is vital to monitor and report on these effects, 'Getting Things Changed' has shown that research needs to go beyond reporting of experiences. Instead, we have tried to unravel some of the culture and the practices which exclude or 'misfit' disabled people, and to find ways to see afresh what we all take for granted. Change is a continuous process, and there is much more to be done. We hope that the tools in this research will be taken forward and developed further.

Our full report, easy read version and separate reports or briefings for each strand of the research can be found on our website: [bristol.ac.uk/sps/gettingthingschanged](http://bristol.ac.uk/sps/gettingthingschanged)



Norah Fry Centre for Disability Studies  
8 Priory Road  
Bristol  
BS8 1TZ

**Contact details:**  
GTC-SPS@bristol.ac.uk

[bristol.ac.uk/sps/gettingthingschanged](http://bristol.ac.uk/sps/gettingthingschanged)

This research took inspiration from the life and work of Dr. Sue Porter (1953-2017), who helped us to see things afresh, using disability as a lens for change.