

# Getting Things Changed

## Final report



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A man wearing a grey flat cap and a grey sweater over a blue shirt is looking down at a blue folder he is holding. He has glasses hanging from his sweater. The background is a blurred view of pink flowers and green foliage. A purple banner is overlaid on the top right of the image.

## Executive 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.

# 1. Introduction

*Val Williams and Caroline Miles*





## 1.1 Introduction and background

In the light of the implementation of the Equality Act 2010 which followed the UK's ratification of the CRPD, the right of disabled people to be able to engage in all aspects of civic and social life should be protected in the UK. However, those rights are not always seen in practice, with disabled people still facing many barriers, attitudinal as well as material. Despite the Equality Act and CRPD's emphasis on pre-emptive and inclusive access things still get done in ways that are not designed with the full diversity of human beings in mind. The Equality Act and subsequent case law are clear that the concept of 'reasonable adjustments' applies equally to a 'provision, criterion or *practice*'; however there are still obvious everyday barriers not only in terms of accessing transport and the physical environment, but also more subtle (but very real) barriers embedded in practices involving time, information, interaction, and the meaning and value attached to disabled people's lives. Moreover, despite the person-centred goals incorporated in law such as the Care Act 2014, the very services that are there to support Disabled people to participate in society without experiencing unlawful discrimination can become abusive (Flynn, 2012), can fail to deliver equality (Heslop et al., 2013) and run the risk of unsustainable cuts from central government in times of austerity (Amin-Smith, Phillips and Simpson, 2018).

'Getting Things Changed' set out in 2015 to understand better the gap between policy and practice, and to see how changes can be made to practices on the terms of disabled people themselves. The research was designed and co-produced with disabled people, with a partnership with Disability Rights UK, and benefited from many disabled people within the research team and the various groups assisting the research.

The objectives that cut through the whole project were to:

1. identify the barriers facing disabled people in the UK, and understand better how social practices get 'stuck';
2. discuss and connect micro and macro theories of social practice, by applying them within the field of disability;
3. explore disabled people's own solutions, and understand better the conditions under which 'co-production' can have an effect on practice;

4. develop detailed understanding of how organisations and practices can be shifted, on the terms of disabled people themselves;
5. recommend what can be done by disabled people, practitioners and policy makers to tackle the injustices experienced by disabled people.

Faced with seemingly intractable problems, we often hear about the 'culture' of services creating a problem, or the 'attitudes' of society. We wanted to unpack these terms, to get a handle on why social practices get stuck in ways that disadvantage disabled people. We chose a wide canvas of different life contexts, including health services, social care support, Higher Education, performing arts and the media. These all play out in different ways and face unique constraints and possibilities. We explore in this report some of the common learning across this wide-ranging project. In brief, disabled people with many different impairments often find that they are like a round peg in a square hole, not quite fitting. Garland-Thomson's 2011 concept of 'misfitting' seemed very apt here. Over the varied life contexts which we explored, including hospitals, social care, TV and Higher Education, disabled people faced a kind of rigid institutionality, where professionals and experts called the tune. These were reflected for instance in the way conversations happened in dementia settings, or the ways in which local authorities unwittingly create barriers to co-production. Institutional ways of doing things did not only happen within health and social care institutions. Everyday life could become shaped so that disabled people faced exclusions –for example in contemporary supermarkets or train stations. Some of our research explored the fine-grained detail of interactions as they occurred, and in common with Antaki (2011) we wanted to use this analysis to make a difference to the way practitioners (service providers, or staff) interact with disabled people.

The term 'practitioner' is used in a very wide sense within social practice theories, although to avoid confusion, in this report we will use the term 'social actor' to refer to anyone who takes part in an everyday practice. We found it useful in this research to use ideas from Shove, Pantzar and Watson (2012) and Hui, Schatzki and Shove, (2017), which helped us to unravel the various types of elements which Shove suggests come together and are visible in social practices, - meanings, material resources and competences of human beings. Together with wider ideas about power and interconnections between practices, we found this way of thinking very useful to help analyse what needs to be changed (Williams and

Team, 2017). If we can understand and unravel a social practice, then we can also see what drives that practice, how it connects with other practices, and how it may exclude or disadvantage disabled people. Conversely, if we can find practices which have been radically altered to become more inclusive, then we can learn from those, by modelling or disseminating them to others. That was a key method in this research, and we were keen to find examples of positive change across the project.

## 1.2 Overview of this report

'Getting Things Changed' collected data in a wide range of contexts, and with different groups of disabled people. **Section 2** of this report discusses findings about the communication practices that happen in dementia groups, and the interactions that happen between people with dementia and others in their lives. That strand of our project collected naturally occurring video data, and analysed the detailed way in which interactions can unwittingly include or exclude people.

**Section 3** took a similar approach, collecting video data with people with learning disabilities interacting with their PAs, and also in a pottery workshop. Both of these sections share a common methodology, of Conversation Analysis, and both benefited from co-production work with groups of people who had 'lived experience', who have taken the research further into practice by producing video material for training and further development.

**Section 4** covers our findings about performing arts, by showcasing a new way of creating music, *Open Orchestras*, to show how practices can be successfully re-imagined. The research collected video data, and reports on communication practices during music sessions. Disabled performers, actors and presenters are not only benefiting from new ways of being musicians; they also are increasingly being seen on TV and in the media. However, people with learning disabilities may be underrepresented on TV, and in **Section 5**, we report on a survey and interviews on this topic carried out by an actress with learning disabilities.

**Section 6** turns the spotlight on our own practices in Higher Education, in the knowledge that disabling barriers are in fact all around us in universities. We report on research which has been co-produced with a group of disabled students, and with disabled staff at the University of Bristol, using an action and auto-ethnography approach.

**Section 7** examines the extent to which 'reasonable adjustments' to practices in hospitals are being implemented across England, and reports on the experiences of disabled patients who took part in interviews as well as wider survey and questionnaire data. Following that, we have another topic relating to Health and Social Care, but one in which we focus on successful change. The team worked in three Local Authority areas where there was a specialist parenting service, carrying out interviews with professionals involved with nine parents with learning difficulties. **Section 8** shows how specific services can be successful in providing support to these parents, and demonstrates how such practices have been changed.

Finally, **Section 9** by Disability Rights UK presents action research which has been carried out with six different groups of disabled people across England, supporting them to make a difference by co-producing social care with local authorities. Some of the barriers as well as the drivers for successful co-commissioning of services are explored here.

The messages which arise from our research will be of value to people with core interests in some of the contexts we describe, such as dementia services, TV producers, hospital staff, social care directors and commissioners, and university diversity officers. However, the wide canvas of our project has enabled us to see the common themes about practices which cut across everything. We discuss some of these in the final section of this report. In brief, we can see across all our data how people regularly accept that things must be done in certain ways, since they have always been done that way: disabling practices are justified by recourse to tradition, rules, and precedent. In order to change practices, it is therefore necessary to step back and work out what is driving a disabling practice. Everything that is done in hospitals, social care, universities or TV could be done in a different way, and disabled people are catalysts for change, helping society to see things afresh and create more inclusive ways of living.

***Our thanks to Dr. Stanley Blue who introduced us to Social Practice theories.***

## 2. Interactions which include people with dementia

*Joe Webb, Val Williams, Marina Gall and Sandra Dowling*



## 2.1 Background and Methods

Dementia is often understood as a tragic illness (Boyle, 2010), but increasingly policy and practice in the UK are driven by the goal of 'Living Well with Dementia' (Department of Health, 2015). Research has started to include perspectives of people with dementia themselves (Shakespeare, Zeilig and Mittler, 2017), and there is a growing literature using Conversation Analysis to explore interactions with people with dementia (Chatwin, 2014; Lindholm, 2008; 2015 and Lindholm and Wray, 2011). This type of research is not generally 'deficit' based, but instead it aims to explore the interaction practices by which other people include or exclude people with dementia in ordinary conversation.

Our initial goal was to find out whether Conversation Analysis (CA) of video recordings of natural interactions could be useful in creating change in the practices of support staff and carers. Our research questions were:

- a) How can everyday decision making be facilitated in people with dementia?
- b) Can workers learn how to improve their practices through video interaction analysis?

We found out early on that one-one personalised support and care were not readily available to people in the earlier stages of dementia, and that it was far more common for people to attend groups. The main body of video data was therefore collected at memory cafes, or at activity groups or day centres, where we sought to film interactions between people with dementia and any other 'conversation partner' as they happened. In all, this consisted of almost 10 hours of video data which included 28 participants with dementia, supplemented by 8 initial interviews and 6 interviews where we took data back to the participants and recorded their responses and discussion.

The collection of video data was largely carried out by Joe Webb, who spent many days familiarising himself with the contexts, and becoming a known participant in the groups. Our study followed a strict protocol approved by the Social Care Research Ethics Committee, to ensure that people assessed as lacking capacity to consent on their own behalf had personal consultees who could give consent on their behalf. Permission to record events or conversations was always sought at the time, and so consent was continually re-negotiated with all participants. We were fortunate in this strand of our project to work with a group of people with early-onset

dementia, at the Forget Me Not organisation run by Avon and Wiltshire Care Partnership (AWP). They advised our research, and three members, Roy James, Harry Davis and Sandy Read, formed a co-research group. They worked with the project throughout, and have contributed to all parts of this report.

We used a 'Conversation Analysis' approach (Sidnell and Stivers, 2014) to examine the data, viewing and reviewing the videos in order to understand better how the 'routine' methods of conversation are adapted or shaped in this context. We also took our key extracts back to the Forget me Not group, who brought their own experience and insight to bear in their responses to the data. They discussed the findings, and also re-imagined how they would like communication to happen. Their insights form the basis of training materials which we have produced, and which have been developed and piloted with training providers and dementia services.

## 2.2 Difficulties faced by people with dementia

The Forget-me-Not group members shared their experiences of being diagnosed, and the panic and the isolation which ensued:

**"I don't know where it came from, for all this panic to set in, and I think that because I've got dementia, all of a sudden I feel I don't have rights. And people who are caring for me, have taken all those rights away from me, and they're doing it for me, and I don't have a say in it. But we've learnt that we have to fight for our rights".**

Staff and volunteers in dementia groups were immensely skilled and dedicated. Those who interact with people with dementia need to ensure that they can adapt to each individual, but at the same time treat their conversation partner as a human being – with the right to make their own choices. In group situations, we saw how difficult it was to achieve this at times, faced with the task of organising large numbers of diverse individuals. Staff used objects, pictures and prompts to carefully plan conversations about the past.

- But we found that conversations could easily become like 'tests', with specific questioning techniques being used that resulted in people with dementia focusing

on their cognitive problems. In the extracts which follow a few CA transcription symbols have been used, which are listed before the references at the end of this section. The following took place during a reminiscence session:

```

Extract 2.1
01 San      I wanted you to tell me a bit about what
02          you used to do for your ↑jo:lob. can you
03          remember (.) when you were employed what
04          your job was =
05 Jim      = fwork
    
```

- In group situations, quizzes were often the preferred activity, and most of our participants and the Forget me Not members generally enjoyed them. However, we saw how the structure of a quiz could put a person with dementia on the spot, unable to answer when they were given their turn.
- In general, it was difficult for the person with dementia when lots of questions were asked at once, and when people asked questions to which they clearly already knew the answer.
- Following the lead of the person with dementia was important, and we saw how sensitively this was done when a person with dementia continually repeated an unlikely fact about his past. The supporter responded by accepting it as ‘news’ but upgrading it to be relevant to the moment.

## 2.3 What makes for successful practices?

The Forget me Not members knew that their own lives had been turned around by peer support:

**“One person’s strengths are somebody else’s weaknesses, and you just turn it around, so that everyone helps themselves....friendship is so important, because friends really care, and they’re not being paid for it.”**

They were keen for us to develop ideas about how peer-peer support might work in practice, and how this might equalise communication with people with dementia. When we looked in detail at the interactions we had filmed, we found the following points:

- A shared interest or passion could create the basis for good communication, with both partners sharing their thoughts, listening to each other and problem solving together. That happened for instance with two people who were involved in a project to restore and develop a medieval barn.
- People with dementia sometimes needed more time to find an answer, or to get their turn in a conversation. Direct questions did not always work, and it was sometimes better to give prompts, for instance by referring to things already talked about:

```

Extract 2.2
01 Jean → Rob you know when you
          know when you went to
02          Kenya
03 Rob   yes
04 Jean  and you’re saying about the queen
05          in Kenya (.) are you
          thinking of Treetops
    
```

- An informal physical setting led to more relaxed conversations, where people with dementia spoke up and talked about their own topics.
- When we say something, there is always some assumption or agenda in our utterance. It was sometimes helpful when conversation partners explained that agenda clearly, so that people with dementia could understand why something was being said, as well as what was said.
- Visual prompts and music were good ways to get conversations going, although they are not a guarantee of successful talk. We saw instances where objects or photos were used to test memory, where the person with dementia could get it wrong. Visual and audio prompts need to be fitted to the person’s interests, and used as a jumping off point.
- Good communication in dementia groups often focused on the here-and-now, and could encourage people to make choices about what they wanted to do, how to sit, what to talk about, and where to go for lunch.

## 2.4 Recommendations for change

It is all too easy for practitioners to say 'All we need to do is to have a good conversation'. But it is not just a matter of being a good conversationalist. People can learn by studying some of the common ways in which things go wrong, and can develop their own awareness of what to avoid and how to improve their interactions with people with dementia.

- Everyone is an individual, and every conversation develops differently as it goes along. Conversation Analysis can never offer a 'cookbook' approach. However, it can be used to reflect and to shed light on the structures of interaction.
- Services and practitioners need to consider how to support decision making in people with dementia. Based on better understanding of the 2005 Mental Capacity Act, supporters and carers can give more time to talking with someone with dementia about their choices and decisions, as we also explore in the next section with people with learning disabilities.
- Practitioners could relax professional boundaries, and share their own stories.
- Quizzes and other organised group activities could be more successful if they were run in more relaxed settings, with a structure where teams could work together, and where there was no one 'correct' response. Staff could also take part in the quizzes more, with a person with dementia running the quiz.

- For Roy, Harry and Sandie, communication matters because it is part of the enjoyment they get out of life. They are keen to tell others that life does not stop when you have dementia, but with good support, you can develop new interests, friendships and a stronger sense of your own identity and rights.

The Forget me Not training videos are freely available to download and use by following the 'videos' link on our project website. They were produced by Moore Lavan Films ([www.moorelavanfilms.co.uk](http://www.moorelavanfilms.co.uk)). They can be viewed by individuals, or used as the basis of training sessions in Dementia organisations or groups.

***Our thanks to Professors Charles Antaki and Celia Kitzinger, who worked with us on the data in this section and the next.***

### Transcription conventions for extracts in Sections 2 and 3.

( . )	Slight pause
( 0 . 5 )	pause timed in fractions of a second
=	an utterance which is 'latched' or follows immediately on the previous one
£	laughter in voice
↑	Upward intonation
↓	Downward intonation
: :	Elongated vowel sound
[	speech which overlaps or starts simultaneously

### 3. Playing with words: interactions with people with learning disabilities

*Sandra Dowling, Joe Webb, Val Williams and Marina Gall*



## 3.1 Methods and background

Ten years ago, a project called ‘Skills for Support’ (Williams et al., 2010) showed that support staff, despite their best efforts, face tensions between the protection of disabled people and the empowerment of their decisions (see also Antaki, 2011; Jepson, 2011; Williams, 2011). Over the intervening ten years, new legislation about decision making has been implemented with the 2005 Mental Capacity Act in England and Wales, the second principle of which requires support staff and PAs to take ‘all practicable steps’ to support decisions. Existing policy and law therefore combine to foreground choice and control, and support for the active agency of all disabled people, including those with learning disabilities. However, there are still tensions, and since 2011, a whole raft of difficult, sometimes abusive and neglectful practices by statutory services have come to light. These issues are not just about statutory services. In 2017 the death was reported of a young man whose bowel condition was exacerbated by his own choices and preferences, which were respected unduly by his support workers in his ‘supported living’ accommodation. It is thus even more urgent to understand better how PAs can provide support which allows people with learning disabilities to become decision makers, and to develop a sense of control over their lives. At the same time, it is urgent that we understand better how to ensure people are safe and that their basic needs are met.

As in Section 2, this part of our research aimed to record naturally occurring interactions between people with learning disabilities and their personal assistants or support workers. We used a Conversation Analysis (CA) approach (Antaki, 2011) in order to explore intervention and change in this type of talk, with the following research questions:

- a) How can everyday decision making be facilitated in people with learning disabilities?
- b) Can workers learn how to improve their practices through video interaction analysis?

Our goal was not just to replicate previous research, but also to investigate how far this type of detailed Conversation Analysis (CA) could be effective in understanding social practices and change.

We collected 9 hours, 6 minutes of video involving nine people with learning disabilities interacting with eight PAs or supporters, in a range of everyday situations such as people’s own homes, going to the shop, visiting a park, engaging in leisure or domestic chores. Some of

our data also took place in a workplace pottery project, where people with learning disabilities were supported by two members of staff in creative activities to produce high-quality pottery for sale. Unlike conventional CA, we also recorded initial interviews and took data back to participants in their dyads to discuss our findings and their learning. These interviews helped us to see more precisely what could be changed.

Finally, we were very privileged in this part of our project to work with the Misfits Theatre Company, a local group of actors with learning disabilities. By viewing excerpts from the video data, they were able to bring their own insights to bear, based on their experience of having support in their lives. They used creative methods to re-imagine the scenes on the videos, and developed and filmed their own drama based on the data.

## 3.2 Interactional practices of PAs and support workers

We found that people with learning disabilities all benefited from good relationships with their PAs or supporters, and were keen to engage with them. All the PAs in this small sample were excellent at offering choices, following the lead of the person with learning disabilities and showing that they were having fun. However PAs were torn between wanting to advise on good choices, for example healthy eating choices, and wanting the person with learning disabilities to have a say about what they wanted. Of 84 extracts we collected where autonomy was foregrounded in the conversation, 57 were initiated by the PA. However, half of those were veiled invitations or proposals, softened by a ‘Do you wanna’ invitation.

For instance, Janet, a young woman with learning disabilities went to a supermarket to buy a snack, and chose a pack of four donuts. The following conversation

### Extract 3.1

```
01 P.A: They've only got four, though.  
           [And you only want  
02           one.  
03 Janet [Oh, no.  
04 P.A: It's the smallest amount they have here.  
05 P.A: Yeah do you want, like a (.) do you want  
           a croissant
```



Despite Janet's persistence in going after the donuts, the PA explained that 'there's no point buying you four', and asked again, 'Do you want a chocolate croissant?' Eventually, Janet agreed. Sometimes offering a choice can sound more like persuasion, since a repeated positively tilted question like 'Do you want' implies that the previous choice was wrong. These were some of the other points which emerged from analysis of these interactions:

- People with learning disabilities carried out some everyday practices with another person present (e.g. shopping) which most people would do on their own. They therefore had to manage both the interaction with their PA as well as the practice itself.

It can be both rewarding but hard work to have a PA in your home, even when she or he is a good friend. The person with learning disabilities had to organise time, keep communication going, and lost some of their privacy. Some of them managed this well by giving the PA tasks to do, and showing awareness of the relationship with their PA. One woman said:

**Extract 3.2**

01 Kia You know what(.)we might not be so rushed today.  
 02 You know like usually rush rush rush rush rush. I  
 03 might if we've got time I might even treat you for a  
 04 cup of tea after  
 05 P.A. Oh thank you

- People could get included or excluded from conversation by embodied practices, which as also true for the people with dementia in Section 2 – for instance, PAs often waited and glanced towards the person with learning disabilities, when doing other tasks, so that they could pick up on cues to get back into the conversation.
- Activity often took over from conversation, when supporters and PAs were more concerned to get the task done, rather than to support the decision making of people with learning disabilities. That happened in supermarkets, but also in the home or in workplaces.
- PAs were generally very good at offering choices by mentioning or showing two alternatives. For instance, the pottery supporter asked if a person with learning disabilities wanted to make a bowl or a plate, and in fact he settled on a mug or a cup. However, at other times, the PA continued to offer a choice for a second time, and then the person with learning disabilities thought their original choice was wrong!

- Based on interviews where we took data back to people with learning disabilities and PAs, staff often felt that there was a difficulty in inhabiting the grey area between professional staff member and friend. These can be contradictory roles, as all our participants did have close relationships with their PAs. Staff also found themselves needing to switch between institutional and non-institutional talk. The bulk of the day consisted of casual chat between the two parties, but it was often the PA who switched back to the task-in-hand: 'What do you want me to do now?' Conversely, in work situations such as the pottery, staff both enabled and encouraged people to participate in the tasks on offer, while some people with learning disabilities wanted to carry on social conversations. Managing both task and talk was quite a skill, but PAs did this effectively by marking the shifts between social sequences and work-oriented talk: 'right' or 'hold that just a minute'.

### 3.3 What makes for successful practices?

It was remarkable in this corpus of data that people with learning disabilities were relatively confident, compared with other CA data (Antaki et al., 2007; Williams et al., 2009) and were largely able to intervene in conversations to bring in their own concerns and topics. They were keen to initiate and to lead decisions, and showed how they could take control of interactions. For instance, we saw how three people found opportunities to talk through future plans and past actions, reflecting on them and wanting feedback from their PAs. One person talked about the reason for certain food choices she had made in the past, and another wanted to talk about how her health needs were being overlooked in college sports sessions, and a third talked about how to manage her fire alarm.

- Successful interactions between people with learning disabilities and their PAs tended to happen when the PA could stop and listen. It was often a matter of having time to follow up what a person wanted to discuss, just as with the people with dementia in Section 2.
- Careful selection of a PA who is a friend was successful, although that did not mean they were necessarily all matched in age or background. The

main factor was trust and getting to know each other well. We saw PAs who relaxed their professional boundaries and shared information about themselves with the person they supported, and that happened also in the pottery workshop.

- Several people in our data showed how it was possible to take ‘executive’ decisions, without necessarily being able to manage every step of the activity. This happened for instance when one woman decided that she did not like the chairs she had ordered via the Internet, and that they should be returned to the shop. This meant disassembling the chairs to re-pack them in their flat-packs, and was something she needed support to achieve. She was therefore in control of the overall decision, even though she would not have been able to implement this by herself. Examples like this help to re-define what independent living means for people with learning disabilities. It does not mean doing everything for yourself, but is more about the control you can take over your support relationships.
- Choice talk can become directive, but here the supporter in the pottery workshop foregrounded creativity over decision

**Extract 3.3**  
 01 P.A. You want a mug  
           know when you went to  
 02 A: or a cup  
 03 B: yeah  
 04 P.A. Well a cups just a mug without a handle  
 05 A: (1) oh yeah  
 06 P.A. we'll have a go and look at the shapes and  
 07 see if inspiration strikes you

- The most successful interactions were based on fun and friendship, and jokes were initiated and enjoyed by both parties. These were sometimes physical jokes, where a person with learning disabilities briefly hid from his PAs, or on other occasions jokes about next-door neighbours or about games being played.

### 3.4 Recommendations for change

The involvement of the Misfits Theatre Company in this research made a big difference. We explored and demonstrated the extent to which creative arts approaches could be used in this type of analysis. It is not only PAs who can learn from interaction analysis, but also the people who are receiving support.

Creating change via direct interventions using CA findings is always going to have limitations, since it generally focuses on local practices of specific individuals. To change the shape of interactional practices more generally, we would recommend some of the following points to be built on data examples or used in training:

- When more than one PA or supporter is present, the person with LD can become side-lined if they do not remain the focus of the conversation. PAs need to think through carefully the rules of engagement if more than one PA is present.
- On the whole we saw good examples of successful interactional practices for building relationships. Using examples from this data could be helpful for the promotion of better practice for other PAs and people with learning disabilities.
- PAs could create more time for conversation, not requiring people with learning disabilities to be ‘active’ at all times. During conversations, it is possible to listen and to support people to make good decisions in their lives.
- PAs and people with learning disabilities need to find situations in which there is a genuine opportunity for an open choice, so that people’s choices are not continually corrected.

The Misfits Theatre Company created a short drama on video, which is targeted at other people with learning disabilities and is freely available to download and use by following the ‘videos’ link on our project website.

## 4. Opening up music: *Open Orchestras* sessions in schools with people with profound and complex disabilities.

*Marina Gall, Val Williams, Joe Webb and Sandra Dowling*



## 4.1 Methods and background

Ensemble music-making can be a practice that excludes many people (Sharp and Rabiasz, 2016; Sound Sense, 2015). That applies maybe particularly to classical music-making, which depends on having an instrument, music lessons, and technical skills. Without access to a musical instrument suited to their personal needs, many children and young adults with disabilities are excluded from engaging in ensemble work. Therefore 'Getting Things Changed' was keen to collect data which focused on a new approach to ensemble music-making in special schools, *Open Orchestras* which has been devised by the directors of 'OpenUp Music'. The use of a new technological instrument – the Clarion – is central to this programme. It can be played on an iPad, using a Satnav (in which a small sensor is placed on the part of the body that the students can move, and which triggers notes on a laptop computer screen) or using Eyegaze. This newly-designed instrument can be adapted to suit most students' physical needs. The *Open Orchestras* programme also offers new musical repertoire for these ensembles.

This strand of the research thus allowed us to take a close look at interactions with 10 young people, aged between 14-21, who had a range of profound and complex physical as well as learning disabilities. The groups included six young men and four women, with two from black or minority ethnic groups (BAME). The central research questions were similar to those in Sections 2 and 3, focusing on 'How can everyday decision making be facilitated in people with profound and multiple learning disabilities (PMLD)?' We were also interested to learn more about *Open Orchestras*, as a creative practice which arguably has changed the face of music making for disabled young people, to conceptualise how change can be made in social practices more generally.

Our data consisted of videos of 6 naturally occurring *Open Orchestras* music sessions and a concert, in two special schools for students with profound and/or complex learning disabilities. Ethnographic notes were taken during the sessions themselves, and footage was afterwards taken back to five staff and one young adult musician. Interviews were also carried out with seven other significant staff members including speech therapists and one head teacher, and with a director of OpenUp Music and the head of the local Music Education Hub. While a Conversation Analysis (CA) approach was used to explore small extracts of interactions which

included the young people, we also position ourselves more broadly as ethnographers in the following summary.

## 4.2 Issues facing young people with complex needs

The young people in this part of our research were all individuals, with their own strengths and needs. However, the majority of them had differences in their communication and understanding, ranging from people with no verbal language to those who had a relatively good verbal repertoire. Many of them also had cerebral palsy, and had difficulties in controlling movements in their limbs, although several had good facial expressiveness. On the whole, however, this range of differences can mean that others might misunderstand their communication, or indeed that there are few channels for them to take up full membership as conversation partners in any setting (Ostlund, 2015). A further point which is relevant to our research is changing perceptions to enable these young people to be recognised as music *makers*:

**“One of the challenges that we’ve always faced, and one of the points of confusion within the sector is this whole thing between music education and music therapy”.** (Doug Bott, a founder of OpenUp Music)

Additionally, this research took place at a time when music education generally was being pushed to the background in school curricula in the UK, despite research evidence (Hallam, 2010) about its benefits for all pupils in terms of creativity, attainment and core skills.

There is thus a range of educational, creative and interactional problems which are faced at many different levels, and which *Open Orchestras* sessions challenge:

- a) There is a general disabling barrier to music education in mainstream as well as special schools: not all schools provide children with regular opportunities to engage in practical music-making.
- b) Prior to the creation of the new technological instrument The Clarion, there were a very limited number of and, sometimes no musical instruments that were accessible to many children and young adults with PMLD – since playing instruments, whether acoustic or electronic, generally requires dexterity. This barrier had previously applied to the majority of the young people in both schools.
- c) Whilst the young people involved in the research study had been offered individual opportunities

to engage in music prior to the advent of *Open Orchestras*, most of the experiences for those with complex physical disabilities were passive.

- d) Another disabling factor in orchestral ensemble music making (for adults and young people) is repertoire. Prior to the development of the *Open Orchestras* programme, there was no repertoire created specifically for ensembles including young people with special educational needs/ disabilities (SEN/D).
- e) The *Open Orchestras* approach can overcome many significant barriers to group music making but only where there is a strong infrastructure.
- f) Even when students in special schools are given opportunities to play instruments, these are rarely available when they leave full-time education. *Open Orchestras* in schools is the starting point for work that can lead to students becoming part of the newly formed National Open Youth Orchestra.

### 4.3 What makes for successful practices in *Open Orchestras* school sessions?

The staff involved in both schools we observed were immensely skilled. Although not all were musicians, it was important to have people who were able to set up the hardware (which could be different for each student) and occasionally adjust or re-set the software. We saw two main models we saw in relation to how schools organised *Open Orchestras* sessions.

**Model 1** Students enter the music space (usually with a teaching assistant: TA) one at a time, where they are met by the music lead teacher. Equipment for music making is set up with the student, TA and with guidance from the lead teacher.

For instance, in one session, the lead teacher comes over to a young woman, Jess, who is sitting in front of a screen to play the *Clarion*, with her TA. The teacher holds a file in which she is reading out the previous goals set by each young person, and reminds Jess that she was going to choose a 'repeated pattern' to play. Jess then plays three notes via eye gaze, and stays longer on the mid bottom note. The teacher describes this as 'making a pathway', and comments: "Lovely so are we going in a square somehow around this edge? I don't want to influence you but that's what it looks like to me (gestures in square pattern on left of screen) you're wanting to hit this note aren't you?"

She goes on to suggest this is like a motif in music, and that Jess could choose which direction to move through the notes. Jess agrees (with a 'yeah'), and is left to practise with her TA listening and encouraging her. The benefit here was that each young person had individual time with their TA and as in the above example, with the lead teacher; this meant that they could become involved in choices about how to set their *Clarion*, as well as the notes they wished to play, and they had time for personal practice, supported by their TA. A challenge arose if the student's TA was required to help someone else or go to another part of the school to collect another young person/adult: the original person could be left alone for a considerable time which led to inactivity or frustration if there were difficulties with the equipment.

**Model 2** Staff set up the equipment prior to the entry of the whole ensemble, so that when students enter the music space there is a very clear start and end to the *Open Orchestras* work and most of the technical problems are dealt with prior to the students' arrival. In one school, the session generally started with instruction for everyone to sit down, and then to be quiet so that they could listen to each instrument in turn. On one occasion, the lead music teacher was absent, but an experienced TA took over, making it explicit that:

**'We listen to the instruments individually (standing up and waves arms) follow a little bit how Joe does it yeah? You know when Joe does it and we're all quiet, and listen to each other's instrument? And then we can perhaps play together a bit (circular movement with hands)'**

The benefit here was an efficient use of time to create maximum opportunity for ensemble music making. The approach was on the whole more explicitly rule-governed, and required students to fit into the pattern. Such an approach therefore suggests the need for alternative opportunities to use the *Clarion* in the week either in school time or at home.

#### **Other useful strategies for organising sessions**

- Having an extra room available to include TAs working with individual students who find working with a group difficult over a long period of time. This helped one young man join in a music session for 12 minutes; his TA noted that this was a huge improvement over his previous span of 1-2 minutes a year previously.

- Orchestral routine could be helpful. In one school there were clear indicators as to when the session started formally, at the beginning of sessions students played their parts to each other, and there was always a period of silence before they performed.
- Particularly when students have physical disabilities and they could not move easily to view other members of the orchestra, it was important that they were made aware of the musical timbres that each student is working with on their Clarion or other instruments. As such, including this as a regular starting point within *Open Orchestras* sessions was vital when working with students with PMLD.
- Sessions appeared to run most smoothly where all of the TAs were confident in setting up and carrying out basic programming of the Clarion.

### **Interactional practices involving the teaching assistant (TA)**

Within *Open Orchestras* the TAs had a variety of roles. Two of the main ones were:

1. Ensuring that the instrument was set up and working correctly, and that the students were physically comfortable and in a position to be able to play;
2. helping the students to know what to do and supporting their own decision making.

For instance, it was common for the music lead teacher to communicate something to an individual student, which then was reinforced or answered by the TA. Since there was a need for the ensemble activity to ‘keep pace’, the TA often needed to mediate discussions between the student and the conductor. It was challenging to ensure that the student’s voice was heard, at the same time as not disrupting the overall work of the orchestra. There were several moments where young people initiated a sequence of interaction with their TA, sometimes by playing their instrument.

On one occasion a young man makes hand shapes on his screen, and is praised by the TA: ‘That’s a good technique Mark’.

### **Stopping and starting the music**

As in any orchestra, stopping and starting musicians is a key task for the lead teacher or conductor. We saw this being done in different ways, with very physically mobile teachers, moving to stand directly in front of a particular student. They variously used combinations of hand gestures; using the student’s name to start or stop them; delivering a ‘stop’ instruction verbally.

TAs also took care to follow the instructions to stop or start, and encouraged students to remove their hand or turn off their instrument when necessary, while the overall task of conducting relied more on gestures and sounds to shape the music. A gradual reduction in volume for instance sometimes heralded the end of a piece.

## **4.4 Changing what it means to make music**

The inclusion of *Open Orchestras* into the curriculum for special schools enables all students to be involved in ensemble music making by reshaping instruments and repertoire around the needs and identities of young disabled people. This constituted far more than a technical fix:

- Young people with complex needs and communication difficulties were concentrating for long periods, were listening to each other, and demonstrated awareness of each other’s contributions and the music as a whole. This had spin-off effects into other areas of the curriculum, for instance as one speech therapist explained: ‘using Eye-gaze with The Clarion in a fun orchestra setting motivated the students to move to use Eyegaze skills for communication too’.
- Students were able to follow instructions, and become part of an ‘ensemble’.
- The ensemble as a whole created music which was novel, exciting and different – even when it was shaped around a traditional classical piece of music.
- The sense of pride in music making were very evident in both students and staff.
- Building up a musical ensemble in this way takes time and rehearsal, like all good music-making, and we greatly enjoyed the ‘end result’ of *Open Orchestras* in public performances given by the South West Open Youth Orchestra. Achieving this requires a source of sustainable funding, rather than temporary project

funding, and the local Schools Music Education Hub has committed to funding *Open Orchestras*, with plans to influence the inclusive design of the new concert hall in the city.

As a social practice, it is clear that music making can be done differently. A visionary, skilled team of people were needed to make the leap into new forms of music, alongside the ambition and enthusiasm of young music makers, and of course their teachers and TAs. Thus it is a clear example of all three elements of Shove et al's (2012) social practices in flux, with 'change' of material resources, alongside changing the meaning and value of music making, and fostering new competences in teaching staff and pupils.

## 5. People with learning disabilities on TV

*Beth Richards, Mike Steel and Victoria Mason-Angelow.*





## 5.1 Methods and background

This strand of the research was started by Beth Richards, an actress with learning disabilities who belongs to a local theatre company in Bristol called 'The Misfits', the same group who supported the research in Section 3 of this report. Beth and her fellow actors were aware that people with learning disabilities were not often seen on TV, and Beth wanted to find out why that was. TV is important, because people watching TV can sometimes form their attitudes by what they see. TV can reflect culture, but it can also change cultures.

Beth's aims were:

- To find out why there are so few people with learning disabilities on TV
- To understand how TV works at the moment, so that we can think more about how to change the practices which exclude people with learning disabilities.

Beth ran an online survey (with 180 responses, about a third of which were from disabled people) and carried out 18 interviews with people in theatre, TV and the media, including three TV actors with learning disabilities, a disabled performer and comedian, as well as writers, performers and non-disabled TV personalities. She asked questions about their views on people with learning disabilities and TV, as well as their ideas on barriers and their experience of negotiating those barriers. Depending on people's experience, she was interested to learn more about existing TV practices, but also to reflect on what people with learning disabilities could offer on the screen.

This strand of our project was an extremely important example of what is known as 'inclusive research' (Walmsley and Johnson, 2003; Nind and Vinha, 2012). It is rare for someone with learning disabilities to be so close to academia that they are able to suggest, promote and design their own research; that is partly because most research has to be planned in advance at the proposal stage, in order to be funded (Williams et al., 2005). While that was also true here, our research goals in 'Getting Things Changed' were broad enough to encompass what disabled people themselves felt was important, and thus Beth was able to start up her own project, with funding as a part-time research associate at the University. She had a research partner throughout the process, but the impetus for the research plan and its activism came very much from her, and her own

personality. Methodologically, therefore, this strand is important in the canon of the various methods employed across the project, and we trust that there will be future routes to impact for her work.

## 5.2 Barriers faced by actors and actresses with learning disabilities

In general, the barriers facing all disabled people who want to work in the TV industry also apply to people with learning disabilities. For instance, we learnt about:

- Physically inaccessible TV studios and audition spaces
- Discrimination against actors who applied for roles which were not specifically focused on disability
- Difficulties in the tight timing of casting processes, when disabled people also have to organise their travel, PA support and manage their disability related needs.
- The financial problems caused by writing and performing being outsourced to self-employed individuals. This meant that there was no source of income during fallow periods.

Beth was invited to join a meeting of the 'Disabling the Screen' group at Sky Studios in 2018, where media champions talked of the institutionalised and rigid ways in which the TV industry works. This echoed the barriers found elsewhere in this research, for instance, in universities (see Section 6). Greater flexibility was needed to increase diversity on TV for all groups, including for disabled actors and actresses.

Beth's research additionally unearthed some specific issues facing people with learning disabilities who want to get into TV.

- Parts available to people with learning disabilities to become actors on mainstream UK television were felt to be limited. Much of this seemed to be about the commissioning process, since there were shows written to include people with learning disabilities – but which did not reach the TV screen.
- The problem was not a lack of talent. There were lots of talented people with learning disabilities in theatre groups in the UK, but TV companies did not work with these groups enough.

- The shows that were commissioned tended to show stereotypical views of learning disabilities - parts were written for people because they had a disability that the audience could identify with (Down 's syndrome, autism). There were felt to be virtually no opportunities for people with learning disabilities to simply act a role which did not focus on their impairment and its issues. As Sarah Gordy writes on her website:
- People with learning disabilities on TV and in other public performances were often aware that audiences or directors praised them for simply being there. They wanted more honest feedback, which did not patronise them because of their learning disability, a theme that was a direct parallel for music makers in Section 4 of this report.

**“I’m a professional actor, dancer and model. I have Down’s Syndrome but that is not all I am.”**

- Actors with learning disabilities told us that there were few TV casting agents who understood and were helpful for people with learning disabilities.
- In addition to physical access problems, actors with learning disabilities found information about auditions or about TV itself too difficult to understand, with technical language and small print. Ironically, there was a total absence of information using other media, including video or other visual media.
- Descriptions of roles in casting calls were said to be very specifically based on appearance, and it was frequently the case that a disabled character or a character with learning disabilities would be played by someone with the right ‘appearance’ but without the experience of having a learning disability.
- Most disabled people felt that the audition process created extra difficulties for a disabled person; however additionally actors or performers with learning disabilities found it very hard to learn scripts, and scripted performance did not necessarily show their talents.
- For the few people who were successful in getting parts on TV shows, the pace at which the process worked could be a barrier to them.
- Actors with learning disabilities who are on TV have often had a lot of support, or a family member who had helped them to get on TV. People may need a personal assistant or supporter so that they can work more independently, but they did not often get that support, and so tended to be seen as in need of a ‘chaperone’, much like a child actor. Part of that was about the difficulty of obtaining funding from the government Access to Work scheme for temporary, intermittent and part-time work.

## 5.3 Examples of success

During the time that this research took place, there were a few striking examples of TV performances by people with learning disabilities. For instance, Toby Sams-Friedman took a key role in the crime drama, ‘Silent Witness’ on BBC 1, in which he portrayed a character who followed his passions, and established a relationship, persuading someone else to escape with him from an abusive situation. The show was far from patronising, with the plot unfolding in such a way that his role ended in a tragic police shooting.

Outside mainstream TV, there were also examples of independent media groups such as Oska Bright who created their own TV and films.

Some of our interviewees, including a successful TV comedian and actor, suggested the possibilities for doing TV in different ways, and the unique contributions that actors with learning disabilities could bring – including spontaneity, personality and humour.

Individual actors with learning disabilities often started young. They had strongly supportive networks around them, often including their family, and like all actors, they told stories of the chance events which had given them their first break:

**“Not really. I sort of have an agent, but they do not help me get work. Mum does most things for me.”**  
(actor with learning disabilities).

Theatre companies of people with learning disabilities, like ‘Mind the Gap’, achieved success in putting on shows in mainstream theatre events, such as the Edinburgh Festival.

## 5.4 Changing the TV industry

There was a strong groundswell of change during this research, fuelled not only by disabled people's demands for change, but also by the need for the TV industry to adapt to the new digital world, where programmes are available on streaming platforms. Part of this change was visible in the way that Beth Richards undertook her research, which was sometimes unconventional and bold in approach, for instance using a Polaroid camera in interviews. She herself became at least in part a symbol of new ways of doing things.

- Changes will come via the desire of actors with learning disabilities to work in TV and pursuing this goal. This would be helped as more people with learning disabilities are seen on TV screens in the UK, since that encourages people to feel that their own, real, 'ordinary' lives are represented in the media.
- Like other areas of life represented in our 'Getting Things Changed' research programme (see for instance Section 9), it became apparent that the TV industry was stuck in ways of doing things that reflected the power of those at the top. In order to

change TV practices, it would be essential for those in powerful positions to learn more flexible ways of relating to people with learning disabilities and disability media groups. That could include joint training, visits to people with learning disabilities on their own territory, and more informal encounters to engender confidence and trust.

- One of the exciting ways forward might be for people with learning disabilities to actually write and produce TV, so that they could influence different ways in which scripts and parts could be learnt and performed. They can make change happen, just as young musicians in *Open Orchestras* in Section 4.
- More accessible information, including information about the TV industry itself, would help to explain things to people with learning disabilities. However, easy information is always of benefit to everyone, and would help to demystify the process of getting into TV for everyone. The reliance on print and text needs to change. A 21<sup>st</sup> Century TV industry could spearhead the way forward in producing information which would be accessible for all.

## 6. Changing academia: disabled students and staff in universities

*Wendy Merchant, Victoria Mason-Angelow, Steve D'Evelyn, Stuart Read, Sheila Trahar, Sue Porter.*



## 6.1 Methods and background

We now move to a seemingly very different context for disabling barriers, Our focus on change in academia started at the point when the Disabled Students' Allowance (DSA) had been severely cut during 2014, with the intention that universities would take responsibility internally for providing an environment in which the need for individual support would be reduced. Following this, provision of individual support at UK universities was outsourced, and in January 2017 guidance was issued by the Disabled Students Sector Leadership Group to vice chancellors and senior managers about 'inclusive teaching and learning'.

This context provided a perfect opportunity for disabled students themselves to contribute to this debate, enabling our own university to develop its strategic plan for greater inclusivity and diversity. The goal was to: "Listen to how disabled students formulate their own experiences of the barriers that they encounter in the higher education environment, and what it takes to improve their inclusion in education." (p.3)

While the research data were all collected at our own university, we know from the literature (Blockmans, 2015; Brown, 2018) and the surge in interest in conferences across the UK that these issues are not unique to Bristol, nor even to the UK (Hanson, 2016). The method followed a participatory model, where student researchers took the lead in planning and in creating a platform for their own agenda, as it developed during the project. Nine students, all female, responded to a call for a 'co-research' group, and they remained central to the research activity in this strand for the first two years of the study, holding 13 group meetings where they reflected on their own experiences at the university. One of the significant gains from this group was their own growing sense of empowerment and peer support, which several of them said they had never experienced at the university previously. They successfully applied for funding from the 2016 ESRC Thinking Futures Festival, in which they held a Forum Theatre event, enacting scenarios based on their experiences, and asking the audience (the 'spectators') to intervene and reconstruct the action.

During the second phase of the project, five of the group created their own personal reflections in written form. Group members assisted the research associate by carrying out interviews (15) with disabled students across the university, and helped to analyse these. Their own

project reached a conclusion before their studies and careers led them away from Bristol, and they took part in a collaborative writing weekend, producing a 'zine' which expressed their experiences as well as their analysis and reflection on what needed to happen in the university.

During the early phases of the research, it became apparent that the disabled students' experience was matched by similar issues amongst disabled staff. This strand therefore expanded its remit, to include a focus on disabled staff in the university and was led by disabled staff in our own project. This part of the strand followed a similar model to that of the disabled students, with an auto-ethnography focusing on ongoing experiences and on the actions taken to tackle disabling issues in the university. Several of the group were also active in their support of the Staff Disability Forum, which had previously struggled to attract membership across the university. The data was subsequently enhanced by 13 semi-structured interviews with other disabled staff members across the university. Data for both the student and staff side were transcribed and analysed using process coding, so that we could describe the shape of some of the practices in which participants' experiences were grounded.

## 6.2 Being a disabled student or a disabled academic

A central finding was that disability in the university was associated with students rather than with staff, although some of the issues in being a disabled academic had parallels with those of the students.

Identifying as disabled was a conflicted process for both groups. While some disabled students felt that it made their support 'legitimate' and explained some of the problems they had been facing, others were strongly independent, and felt embarrassed to 'ask for help'. For disabled staff, matters were even more difficult, since identifying as disabled did not necessarily bring with it any benefits in terms of support. Not all impairments are visible, and both students and staff who had hidden disabilities were more likely to a) not 'disclose' or identify themselves as disabled; b) to start talking about their disability at later points in their career; c) to have to repeat their issues and needs more frequently to different people, a major barrier for both students and staff.

*"I guess what I really wanted to see was my personal tutor recognising this and then speaking to me about it, and seeing how I was feeling about it"* (Student, 05).

Conversely, those with visible impairments, for instance with mobility aids such as wheelchairs, had a slightly different journey, and their initial 'set up' of support was important. Students who had met an assessor from Disability Services prior to starting at the university reported how valuable this was, since otherwise they felt they were always 'playing catch up'. Amongst disabled staff, however, even where their impairment was evident, there were major gaps in support or advice. Members of the Staff Disability Forum reported that they had not even known about the government 'Access to Work' system to which they could apply.

Here are some of the other common themes across students and staff:

- **Feeling on your own** Although DSS services were generally welcomed by students, and felt to be friendly and helpful, there was a general theme about disability being seen as a problem in the flow of academic life. Therefore, the goal of the university seems to be to make the disability 'invisible' or to ignore it. The same theme was just as true for disabled staff, who felt that they were left on their own to manage their disability related services such as Access to Work and indeed their disability: "It's kind of like, you're disabled, this pot of money is here; apply for it. You're on your own. Go". (Staff, 004)
- **Being assessed** was a common experience for students and staff, with Access to Work, Occupational Health, Human Resources and Disability Support Services variously involved. All this can involve emotional and physical labour, simply in managing the meetings. Assessments were described as 'intense', 'intrusive' and 'tiring', and some felt there were too many boxes to tick, not all of which were needed. However, DSS staff sometimes did manage the assessment in a personalised way, and we saw how the detail of interaction mattered here in universities just as it did in the various settings explored in Sections 2 – 4 of this report: "She (the DSS staff) made it such a way that, you know, it was easy to talk...you know, it was easy for me to express myself and talk. She asked lots of open ended

questions and respected my pauses to think before answering". (G1)

- **A lack of transparency** was experienced in the system for allocating resources for students as well as resources to staff who qualified for 'Access to Work'. What does it take, for instance, to be allocated a laptop, or a particular type of technology that you see others using? How does funding get allocated to staff on temporary or part-time contracts?
- **Timetabling and room allocation** were frequent issues, both for disabled students and staff. Given the problems faced by this University with physical access, a common response is to re-allocate accessible rooms according to need. However, this process could mean frequent journeys from one end of the campus to the other, making it impossible for disabled staff or students to manage. For staff, having their timetable in advance was essential, so that they could check out each individual room for accessibility. For students, their unit choices could depend on the way in which the timetable accommodated their needs.
- **The interconnection between different practices.** There were many complex barriers in the lack of connection between practices, both for students and staff. For instance, taxis might whisk the disabled student away before s/he could stay and chat after a lecture. Sitting in a wheelchair at the front of the lecture hall means that you constantly have your back to others. "people are waiting for a lecture, they'll be waiting in one place, like at the top of the stairs, and I'll sort of be in another place, sort of thing". (Student, 08) Travel help was only provided to academic buildings, and so students sometimes found it impossible to get to the student union and access social events, while staff were left in limbo having to book their own travel because of access arrangements on the train.

## 6.3 What could work better?

Although it was centred on one university, this research has some key messages for all. The central point is about how disability is viewed in universities, and how that is reflected in university practices. We found that it was common for disability to be seen as a problem, or as 'ill health', and so the response tended to be to fix the problem – making the individual student or staff member feel as if they themselves constituted the problem, or did not fit in the university at all. Therefore our central point for universities is to consider what a social model of disability would look like in practice. This would go beyond 'ticking the box' of legal obligations, and would mean not only providing efficient and helpful support services, but also moving towards an inclusive approach, where disability becomes part of the norm, just as we explore further in hospital settings in Section 7. This research has strongly argued that disability should be seen as an asset, with universities valuing and attracting disabled students and staff to join them. What would that take?

Inclusive practices in universities would include:

- **Information, communication and transparency for all.** Accessible routes between buildings or within buildings, online and hard copy floor maps of rooms for teaching, and a map of the communication between different agencies and groups in the university would be valuable for everyone. There should be a central point about disability related information. Additionally, universities need to be more transparent about who is responsible for which policies and practices.
- **Flexibility built into assessment and review practices.** The timing of assessments can be altered for disability reasons amongst students, but some PhD students still found the demands to be inflexible, and the timing of assessments generally needed to be more spread out. Assessments should recognise different learning styles amongst all students. Similarly, the pressures on staff to produce academic outputs caused difficulties, because of the additional labour of managing disability and support systems. A more inclusive university would review its core values, to move away from individualism and towards greater valuing of team work, where different people contribute differently. This is true for staff as well as for students.
- **Physical environment.** It was suggested by students that a range of seating should be available in all lecture halls or teaching rooms, with a more friendly and relaxing environment – for instance, quiet 'chill out' spaces. These measures should also include the front stage, where a disabled lecturer also needs to have access to the space, the podium, and/or to sit down as needed. The problems of getting to buildings could be facilitated if the university took responsibility to work with the City Council on the quality of road surfaces and pavements.
- **Online library systems** and media site (recording of lectures) were all appreciated, as were the awareness and support given by librarians. However, these systems could be better understood and disseminated to all teaching staff.
- **Valuing and communicating openly about disability** In order to have a more inclusive environment for everyone, universities could use their publicity strategies, imagery and welcome statements to encourage more communication about disability. When disabled people are in senior management roles, and are valued for their contributions, it should become the norm to talk more about disability and to feel safe in doing that.

## 6.4 Next steps towards change

Our own university is taking on several key strategic points from our research, and the legacy will be seen in:

- a) The implementation of a tool to monitor and track progress towards inclusivity for disabled people.
- b) The Forum Theatre training model created by the disabled students' group which will allow future groups of staff and disabled students to explore the issues they face in detail.

Despite progress towards inclusion, it is essential for universities to have a forum for disabled students to have a voice, and also for disabled staff. In our own university, the Staff Disability Forum is now playing a key role to represent the views and issues faced by disabled staff, and to feed into new developments in the university. It is also important to enable a forum for students to develop via the Students' Union. Ultimately, a key step will be to create better networks for disability across universities, a goal which we hope to pursue.

## 7. Reasonable adjustments in hospitals

*Pauline Heslop, Stuart Read, Sue Turner, Chris Hatton.*





## 7.1 Methods and background

As noted at the beginning of this report, the 2010 Equality Act requires services – including health services - to make ‘reasonable adjustments’ for disabled people so that those services are equally accessible to them. This legal requirement is especially important in the light of continued concerns about mortality amongst disabled people in hospitals. For instance, Heslop et al. (2013) showed that people with learning disabilities were dying between 13-20 years sooner than the general population, with many of those deaths avoidable and traced to insufficiencies or poor practice in health care.

Similarly, Thornicroft (2013) reported that excess mortality amongst those with the most disabling forms of mental illness is not the result of higher suicide rates, but rather a combination of socioeconomic and healthcare factors as well as clinical risk. We know therefore that there are continued problems for certain groups of disabled people in accessing health care on an equal basis (Francis, 2012). One recommendation of Heslop et al. (2013) was for an annual audit of reasonable adjustments, with best practice shared across organisations, and it was that which led to this part of our research.

This strand thus focused on the ‘meso’ level of change in organisational and service responses. We aimed to find out more about the facilitators and barriers to the provision of ‘reasonable adjustments’ within the NHS for disabled patients. The specific research questions addressed were:

- a) What strategies have well-performing NHS Trusts taken to ensure the provision of reasonable adjustments for disabled people accessing hospital services?
- b) How is the provision of reasonable adjustments for disabled people in hospital settings monitored?

This strand consisted of five main activities:

1. An Audit of Care Quality Commission hospital inspection reports. This involved reviewing 137 CQC inspection reports from 2015 and 2016 of hospitals that had more than 50 beds, to establish the types of reasonable adjustments that are reported.
2. An online survey (52 responses: 41 patient experience individuals working in hospitals, and 11 Healthwatch representatives).
3. Freedom of Information requests to NHS Foundation Trusts and NHS Trusts in England, regarding their adherence to Monitor (2015) criteria for people with learning disabilities.

4. Interviews (21) with disabled people about their experiences of reasonably adjusted hospital care and their ideas about how hospital services could make positive change.
5. Four workshops in Bristol and Leeds, for disabled people and health professionals to share their good practice examples of reasonable adjustments.

This strand was organised by a disabled academic with a wealth of lived experience as a hospital patient, and also benefited greatly from a pan-disability advisory group, who met several times to shape and interpret the findings as they emerged.

## 7.2 Patients’ experiences

An overarching theme in hospitals was the potential ambiguity about what is meant by a “reasonable” adjustment. What is reasonable to one person may not be considered reasonable by another person or hospital, which means that there is a lack of consistency about what disabled people can expect. There was also ambiguity surrounding the distinction between reasonably adjusted care, and good care practice that any individual should expect regardless of whether they were disabled or not. The Freedom of Information requests on Learning Disability adjustments revealed for instance that of the 186 clinical commissioning groups which responded, only eight had a system for monitoring reasonable adjustments.

The 21 interviews we carried out were with disabled people, most of whom did not have learning disabilities, but a range of other impairments. Their experiences however also reflected the patchy pattern of provision across the country, with a) inconsistent flagging or identification of disabled people and their needs; b) lack of understanding of their needs both by hospital staff and related employees (including transport staff); c) inconsistent staff communication about reasonable adjustments, which often did not happen at all.

Some of the points about their experiences in hospital were:

- **Hospital staff not thinking about reasonable adjustments or how typical hospital practices may be disabling** – disabled people spoke about how hospital practices may unintentionally restrict disabled people’s ability to engage in health care (e.g. calling a patient’s name if they have a hearing

impairment, or using standard print to highlight that large print text can be requested).

- **Disabled people having to ‘fit’ existing hospital practice regardless of whether this would be suitable to their needs** – Examples here included treatments or investigations which take place on inappropriate beds for a person with physical impairments.
- **Disabled people feeling that it is their responsibility to request reasonable adjustments and ensure these are in place** – Because of the need to continually pursue their rights, disabled patients felt that these requests were sometimes met with negativity, resulting in them being seen as a ‘difficult patient’. This could include for instance requests to use a personal wheelchair in hospital.
- **Concerns around ‘becoming a patient’** – Being a patient intersects with being a disabled person, and both roles could be disempowering when in hospital, where medical expertise had the last word. Becoming a patient often masked the identity of being disabled, and so the disability could be ignored.
- **Inconsistent use of accessible information** – Despite the introduction of the Accessible Information Standard, provision and awareness of accessible information was patchy.
- **Inaccessible physical features of hospital environments** – This included not just the hospital itself, but also the connections between practices such as transport and parking, with hospital transport and ambulances not being wheelchair accessible, and limited attention given to ensuring effective disabled car parking.

Participants in this research often valued the excellent treatment they had received from individual hospital staff, and were aware of the stress of austerity and job shortages in hospitals. They were worried that reasonable adjustments may be seen as something ‘extra’ that cannot be accommodated in the current climate of the NHS.

## 7.3 Examples of good practice in hospitals

Our research has shown that some hospital staff and trusts are providing effective person-centred and reasonably adjusted care. For instance, workshop participants from hospital trusts shared several good practice examples such as the following:

- a) Development of a policy and pathway to help promote abdominal aortic aneurysm screening for adults with learning disabilities who were under-represented in service use.
- b) Development of an individualised treatment programme for a woman with learning disabilities and complex needs, who had a fear of hospitals and medical interventions. The woman’s treatment programme involved her receiving a general anaesthetic at home, being transported to hospital under anaesthetic to have her surgical and other procedures, being transported home again still under anaesthetic, and then recovering at home with theatre staff in attendance.

In the interviews with disabled patients, one participant mentioned acting as a volunteer within their hospital, highlighting the changes that they introduced and feeding in disabled patients’ points of view. In particular she noted that the disabled automatic door opened and closed too quickly, meaning that this was causing problems for individual patients. She contacted maintenance staff and got them to slow the door opening and closing. The detail of practices is key to change, and disabled people’s own voices and expertise can be used to positively support change.

Disabled patients also highlighted the general ‘anticipatory’ duties of the Equality Act, which would ensure that hospitals simply became more inclusive of all diversity amongst staff and patients. One interview for instance focused on a recently adapted hospital, where accessibility, informality of procedures and easy information were available to all.

## 7.4 What will support change in the NHS?

Our workshops and advisory group discussions have highlighted that where positive change in terms of provisions of reasonable adjustments have been introduced, this was often because of the actions of individual members of staff. There is rarely a consistent and clear message to improve provisions of reasonable adjustments from senior levels within hospital organisations. This also means that good practice is not kept within the hospital if the member of staff were to move posts. There was also a strong tendency for reasonable adjustments to be viewed as something associated with people with learning disabilities only. There is a need for a more strategic approach, so that all disabled people have access to reasonable adjustment, with senior staff in hospital trusts taking responsibility.

- Clinical Commissioning Group assurance processes need reviewing, to ensure that those they contract to provide a service are doing so within the legal framework of the Equality Act 2010, and such provision is appropriately audited. Care Quality Commission inspection reports of hospitals require a standardised way of documenting the adequacy of reasonable adjustments for disabled people, as well as the responsiveness of services to disabled people's needs.
- NHS Trust policies require strengthening to ensure that hospitals are meeting their legal obligations under the Equality Act 2010. Such policies should describe arrangements for the identification, recording and provision of reasonable adjustments for disabled people, so that hospital staff are clear about their responsibilities and disabled people should not have to continually explain their needs and/or agreed reasonable adjustments to every staff member.
- Consistent and routine flagging of disabled people is needed, across departments and hospitals, and which adequately records disabled people's needs and reasonable adjustments
- Existing policies and practice may be too narrowly focused on people with learning disabilities; messages and learning could be extended to other groups of patients, including those who may not consider themselves to be disabled (e.g. older people).

Our specific recommendations for changes to hospital practices are to:

- Evaluate and audit reasonable adjustments in all hospital trusts, and make these audits publicly available.
- Record and store examples of reasonable adjustments, so that they can be shared and become more sustainable.
- NHS Trusts must listen to and involve disabled people in the shaping of hospital services, to ensure that reasonably adjusted care is being provided. Hospital trusts could employ disabled people as champions of care and quality checkers, with effective co-produced programmes with disabled people to review and improve healthcare practices. Further, disability needs to be valued amongst NHS staff, in the same way as we have argued for disabled staff in universities in Section 6.

Hospitals are institutions where a wealth of experience, expertise and technical services are provided to everyone in the community. However, hospital practices can easily become institutionalised and rigid, since they are part of complex systems where interconnection between assessment, admission, treatment and ward practices are key to a successful experience for the patient. In order to ensure that this complex system really does encompass diversity, a shift in values is needed. Trusts should recognise the importance of reasonable adjustments which not only create a more positive experience for disabled people but also improve hospital efficiency.

## 8. Successful practices for supporting parents with learning difficulties

*Beth Tarleton, Wendy Merchant, Nadine Tilbury, Danielle Turney*



## 8.1 Methods and background

Several of the strands in 'Getting Things Changed' highlighted tensions between competing drivers of practices, but nowhere is this theme clearer than in support for parents with learning difficulties, where the rights of the child may be seen to be in tension with the rights of parents. Despite UK legislation and policy (Children Act 1989; DH/DoE, 2007), parents with learning difficulties are more likely than others to have their children removed from their care (McConnell and Llewellyn, 2002; Masson et al, 2008). Parents are seen as neglecting their children because they do not have the resources, knowledge, skills, experiences and support they need (Cleaver and Nicholson 2007) while professionals are regarded as not having the necessary time, skills and support to work with them (Tarleton et al 2007; DoH/DoE 2007; Jones 2013). Previous research has underlined the tension between child protection in these families, and support for the parents. The result is that some of these families have reported a high level of emotional distress, especially where children were removed, and a consequent distrust of social services in their lives. However, there is an increasing awareness and guidance about how parents with learning difficulties and their children can be positively supported via adapted materials, support services and additional time (DoH/DoE 2007; WTPN, 2016; Tarleton and Porter 2012; Tarleton & Turney, 2013).

This strand of the research aimed to investigate in detail what 'successful' support for parents with learning difficulties looked like in three Local Authorities which had specialist teams for parents with learning difficulties. A case study approach was used, with structured interviews with nine parents and the 37 professionals/practitioners they had each worked with. We also interviewed eight service managers and one commissioner. Data were analysed thematically, by group and across the dataset, with an important feature of the analysis being the discussion of themes within a diverse research team, which included perspectives from health services, learning disability services, children's social work, and policy, modelling in a small way the different perspectives that would exist in multi-agency teams.

The sites included were recommended as sites of 'successful practice' by professionals involved in the Working Together with Parents Network ([wtpn.co.uk](http://wtpn.co.uk)) which supports professionals working with parents with learning difficulties.

This strand has used the terminology 'learning difficulties' to signal that these parents did not have a diagnosed 'learning disability'; nor did they have support from the Learning Disability team.

Finally, two advisory groups worked with this strand. One was a group of professionals and academics, and the other was a parent advisory group who guided our approach to working with parents and provided really insightful questions for professionals which helped us uncover professionals' 'meanings' about parents. The parents group was instrumental towards the end of the project in producing a video to make these findings accessible to other people with learning difficulties.

## 8.2 What we know about the tensions in supporting parents

This research focused entirely on what constituted successful practice, although of course this was only possible because of the contrast with what we already know about the tensions in this area. No prior assumption was made about what constituted 'success', so that the concept could emerge from the data. Specifically, it was not assumed in advance that 'keeping the child in the family' was necessarily a criterion of success in every case. Nevertheless we know that families where children are removed continue to experience distress over long periods of time, as was the case in the majority of parents involved with this study.

Some of the tensions which emerged during the research included the following:

- Parents felt that some of the professionals they had worked with had negative views and assumptions. However, all of the parents usually had a positive relationship with most of the professionals they were currently working with.
- Professionals may be forced by 'systems' to work in ways that challenge their professional standards and ethics; for instance, they often knew that parents need long-term support, while being under pressure to either close the case or escalate to court proceedings for child protection.
- Time was one of the biggest disabling practices or barriers. Practitioners often had problems finding the amount of time needed to work effectively with the parents; parents also needed long periods of time to

learn new skills. There were also competing pressures in managing the timetable required by the child, and also sometimes the resources required that needed to be authorised by management.

## 8.3 Principles of successful practice

Successful working with parents with learning difficulties took **time, trust, tenacity, truthfulness, transparency and a tailored response**. Anonymised composite case studies were created from the data, and 'Janine's' story illustrates these principles:

**Time** Janine is in her twenties, and is a single mum to her four year old daughter, Bella, having had an older boy removed from her care when she was a teenager. During the pregnancy with Bella, however, support was started early, as Janine's wider family had expressed concerns, and an 'early help worker' was introduced. Over the time of the birth and Bella's first four years, this worker carried on visiting regularly, with a whole team approach with an advocate for Janine being introduced later on.

**Truthfulness** Prior to Bella's birth, the early help worker developed a good relationship with Janine's family and had some '*frank conversations*'. Bella's social worker made it very clear to the family that if family support was not available, when the baby was born Janine would be placed in mother and baby placement.

**Transparency** The focus of the work with Janine was to ensure positive outcomes for her child, Bella. For instance, the "Signs of Safety approach" was used in Team around the Child and Child in Need meetings to ensure Janine understood what the worries were, what's working well, and what needs to happen. After these meetings, an easy read summary of the meeting was sent, and explained to Janine, which was slightly more formal. The worker from the Specialist parenting services also used the "I-Thrive approach" to structure their support. The 'success' of support was judged in relation to the professionals' concerns and goal based targets included in the Child in Need plan.

**Trust** Janine had a positive relationship with all of the workers with whom she has been involved for the last five years. She says they '*sat down and talked to me*'.

**Tenacity** As Bella grew up work was done to enable Janine to understand Bella's emotional needs and to enable her to play appropriately with her. Even though there are now no concerns about Bella's welfare, she is still in frequent contact with the health visitor and knows she could ring the health visitor or worker from the specialist parenting services if she needs help or is worried about something.

**Tailored response** Janine's story has a happy ending, in that there are now no concerns about her child's welfare. However, along the way, professionals had to work together across a multi-agency team, including midwives, health visitors and social workers. The key to their success lay in their initial thorough assessment of the situation via a Parent Assessment Manual (PAMS), and also in their continued responsiveness to issues as they arose. As Janine herself said, 'Whenever I need help, they step in'. Janine was recognised as being '*grabby*' with the baby and missing Bella's communication cues. Video interaction training was used help Janine '*learn how to communicate with Bella*' and interact with Bella. Psychological support was also provided to her mental health, to enable Janine '*reflect on past experiences with her older child*' and to support with her on-going contact with her son. Janine was shown how to do her cleaning and supported with her finance and budgeting. As Janine said, '*She does it step by step and if I don't understand she'll say it again and again and again and again.*' When the worker from the specialist parenting service stopped providing specific support, she gave Janine a book reminding her of all the different things she had learnt that she could refer to.

## 8.4 Changing practices to support parents with learning difficulties

Despite having previous children removed, parents involved in this study had, at this time, at least one child in their care. Our research showed that parents with learning difficulties can be supported to succeed, given time, trust, tenacity, truthfulness, transparency and a tailored response to each parent with learning difficulties.

The specialists services appeared to be working in two ways:

- **Consultation model** - parental learning disability specialists were called in to support or advise other practitioners such as health visitors / school nurses;
- **Hub model** - in which specialists at the centre co-ordinated all other practitioners' involvement with the family.

All three services were driven by health professionals. They were based in both adults and children's services and supported other professionals in their relationship-based approach and tailoring their support to the needs of the parents. In one area, professionals from the specialist parenting team spoke of supporting other professionals to understand parents better through meetings in which the detail of the case was discussed. This allowed sometimes negative assumptions about a particular parent to be explored and, on occasion, challenged or re-framed, allowing a more positive, helping relationship to be established.

In general, the principles set out in the Good Practice Guidance on Working with Parents with a Learning Disability (DoH & DfES 2007, WTPN 2016) were relevant to all these cases, even though many did not know

that this Guidance existed, nor did they necessarily know about local policies. Some of the professionals naturally worked in a tailored respectful way with parent while others were influenced by the positive example and practice of the specialist parenting service. Within this part of our research, Elizabeth Shove et al's (2012) version of social practice theory was felt to be particularly relevant, as it shed light on the drivers for changing support practices for parents with learning difficulties. One of the key elements that underpinned successful support practice was a shift in the value afforded to these parents. Professionals believed that parents did not deliberately neglect their children but needed advice and support in order to ensure the welfare of their children. This belief underpinned how they worked with parents to provide effective support. These professionals had developed or sought out the appropriate knowledge and skills in order that they could support parents.

Specialists in working with parents with learning difficulties, whether individuals, in teams or in hubs were a key resource. They were able to gather and share expertise, drive activity, set the appropriate speed and direction of family work, and link with every practitioner involved in a case, to ensure a holistic, family-focused approach. Change which relies on individual staff members' skills and enthusiasm was also seen in hospitals in Section 7, and will be evident again in Section 9. However, this can make change unsustainable, when staff members leave their posts. It was thus important here to see how these champions of change could also provide consultancy or training for other professionals, co-opting them into a more positive way of understanding and working with parents with learning difficulties.

## 9. User-driven commissioning: disabled people's organisations and co-production

*Bernd Sass, Anna Denham (Disability Rights UK)*





## 9.1 Methods and background

The principles of co-production were at the heart of ‘Getting Things Changed’, recognising that good disability research must have disabled people at its core. In the same way, UK social and health care policy have recognised since the 1970s that user participation is essential to public services; the concept of co-production now underpins person-centred care and personal budgets. In health care, the Expert Patient programme introduced a model of patient participation in their own care and this theme is now reflected in mechanisms such as Healthwatch introduced in 2012. The statutory guidance for the 2014 Care Act defines and promotes co-production, introducing the concept into every part of the social care process.

However, one of the problems in co-production is that there is little agreement on its definition. For instance, it can be seen simply as involvement in producing public services, as Alford (1998) reported in Australia, whereas Bovaird (2007) emphasises the regular, long-term relationships between parties in the co-production process. At all events, equality and reciprocity are at the core of what it should mean.

**“Co-production means delivering public services in an equal and reciprocal relationship between professionals, people using services, their families and their neighbours” (Boyle and Harris, 2009)**

Despite the policy drivers, the rhetoric of co-production is easier to articulate than the reality (Scourfield, 2015). We know for instance that co-production requires a power shift in the way things are done. We also know that not all disabled people will want to take up active roles in co-production, in the same way as not all non-disabled people are active participants in civil or political society.

This strand of our research set out to conduct an appreciative inquiry of ‘user-driven commissioning’, with an action approach to supporting disabled people’s organisations (DPOs) in order to achieve deep level changes in local authority practices. The plan was to identify specific projects which DPOs wished to undertake, and in areas where there was agreement from the local authority to go forward with shared goals to achieve change in commissioning practices. The central purpose of this strand was to learn lessons about how disabled people can effect changes on the systems, outcome measures and attitudes of professionals, as well

as their own personal life changes. The specific research questions were:

- a) How can interactions between disabled people and commissioners best be understood and modified, both in mainstream commissioning and innovative approaches such as user-driven commissioning?
- b) What happens in the process of ‘letting go’, that is when practitioners and commissioners learn to place trust in the insights that disabled people have in their care and support, and does this change over time?
- c) What are the impacts on well-being of both disabled people and staff, and on health outcomes and independent living of disabled people?

Ethnographic data were collected in six sites, with at least three others which were approached for initial discussions. In all, five sessions of engagement or consultation were observed, and 16 interviews were conducted face-to-face, four with local authority commissioners or directors; nine DPO members or young disabled people; one local councillor, and two workers or facilitators. Documents relating to commissioning specifications were collected and analysed as well as email communications between the partners. In two of the DPOs, a specific intervention was put in place, with an independent facilitator to support the DPO in gaining confidence to work with the local authority.

## 9.2 Barriers to co-production and user-driven commissioning

Some of the barriers DPOs faced during this research were familiar ones, and reflect what we know about how easy it is for co-production to become a mere box-ticking exercise for local authorities. For instance, we saw evidence that:

- There was a perception that disabled people were not ‘capable’ of taking part in commissioning, and that limited their involvement. Related to this was the view that disabled people would only come to the commissioning table with their own specific issues, and would not truly represent the wider community.
- Interactions observed sometimes included very leading questions, such as this:
  - Worker suggests: ‘Community clubs?’
  - Disabled people say ‘yes’.
  - Worker: ‘What sort of clubs, like discos?’
  - Again, the response was yes.

The patterns of interaction, with closed or positively tilted questions, were similar to those explored in Sections 2-4 of this report.

- Lack of trust fuelled a ‘them and us’ mentality within the local authority at times, which then was reflected back in the DPO groups, resulting in a lack of self-confidence or belief amongst disabled people that things could be changed.
- Practices in local authorities tended to exclude disabled people, for instance by driving processes forward with unreasonable timescales. There were times when ‘confidential’ documents or information were not trusted to disabled people, and in general, professionals tended to set the rules of engagement with DPOs. This resulted in disabled people assuming that the professionals were more important than them and that they should be in control of the process.
- In some areas, there were problems in pursuing co-production or joint work on commissioning, since individual disabled people were being hit by budget cuts, and some were in dispute with their authority about their personal rights and needs. There was thus a perceived conflict of interest.
- Institutionality, in terms of rigid ways of conducting affairs and producing tender documents, was reflected in the professional jargon and vocabulary of local authority processes. This made things very hard for disabled people to participate on a basis of equality, just as in Section 5 in the TV industry, or in Section 7 in hospitals.

### 9.3 Drivers towards co-production: giving up positions of power

- The starting point for a genuine piece of co-production or co-commissioning is that all the partners have a specific project and shared goal which they want to achieve.
- Sometimes the local authority commissioner visited with a group of disabled people on their own territory, and on their own terms. For instance, a group working on a tender could work directly with the commissioner. As one disabled person said:

‘So the first meeting was here [local cafe] they said, “We’ll meet you somewhere where you’re comfortable, we’ll discuss it.”

- Informality and accessibility were two drivers of good co-production. For instance, it was very helpful in one case to have a facilitator who could make things more oriented to the language and style of the disabled people involved. Prior to that, commissioners had worked directly with disabled people, but were a little too ‘business like’.
- Providing training on how to evaluate bid responses in a commissioning process, and how to score them empowered service users and gave them confidence.
- Mutual trust needed to be part of the process, and that might take time, informal meetings and increased familiarity. Sharing documents and information fully with service users should then become the norm.

In terms of our initial research questions, we were able to evidence how:

- a) Interactions between disabled people and commissioners sit at the heart of any co-production process; for user-driven commissioning to work well, commissioners need to step down from their ‘powerful’ positions, and learn from DPOs how to manage meetings, communicate without jargon, and relax the boundaries of a professional encounter.
- b) ‘Letting go’ was indeed the key to good co-commissioning, and resulted in commissioners admitting their mistakes, taking on the information given from disabled people and treating it as important within their commissioning criteria. It was also important when they went back to the disabled people involved, recognising their input and giving them full feedback.
- c) There were a range of impacts recorded by disabled people who had taken part in commissioning work. For some people, the process seemed meaningless, and it was hard for them to reconcile it with their own goals and needs. That happened when there was a slow engagement with the local council, or officers were unresponsive to the timescale on which the DPO was operating. However, in other sites, disabled people reflected positively on ‘Giving something back’, ‘feeling more confident’. Specifically, ‘being listened to’ had a very positive effect and one person commented that: “I feel that I’ve ...got incrementally better with everything where I’ve been involved.”

## 9.3 Deeper level change in the practices of commissioning

Current practices in user-driven commissioning are clearly very diverse, and even within the small sample we followed in this project, there were some councils caught up in austerity measures, changes and government targets, effectively preventing them from spending the time needed to engage with local groups of disabled people on specific projects. We saw examples of initiatives where decisions had already been made, and so even a consultation approach proved rather superficial. This is despite existing evidence (Woods et al., 2011) that budgetary reductions can be achieved more effectively by focused, joint work with local disabled people. For change to be sustainable, greater trust needs to be fostered between disabled people and contracting authorities, with reciprocal learning taking place. Commissioners have to acknowledge and trust that the lived experience of disabled people is invaluable in shaping deeper level changes in commissioning, so that it meets the needs of disabled people.

- a) Disabled people should be in positions of power within the local social services department, and also in the local Council. Bridges can be built, mutual understanding fostered and earlier opportunities for co-commissioning seized.
- b) Practices in social services departments tend to be hierarchically based, formal and risk averse. That clouds any understanding of the social model of disability and what it has meant in the recent history of disabled people. Therefore, disabled people leading training from 'within' councils could re-set the value base underpinning commissioning and other practices, just as in universities in Section 6 or in hospitals in Section 7.
- c) A Disability Equality commission within the council will enable disabled people to be 'on the inside' and to then work more effectively with local disabled people's groups.
- d) Joint training for professionals and service users is of huge benefit, specifically around the tender process. One commissioner who had taken part in joint training commented that they were all 'part of the team'. Learning together fosters equality.
- e) Disabled people's organisations need to retain their power and their wide membership, respecting all impairment groups within a thriving organisation. Clearly this depends on continued investment in DPOs, an essential first step in any successful co-production.

# 10. Conclusions: social practices and change

*Val Williams*



## 10. Conclusions: social practices and change

Our report has covered many different contexts, impairment groups, and life stages. Therefore, some of the findings we report are naturally specific to those contexts. We draw together here some of the themes which thread through our report, so that we can understand more clearly how social practices can exclude disabled people (our first project objective) – and how they can be changed (our fourth objective).

- **Our first theme is institutionalisation**

Practices which involve disabled people are often driven by power structures, in which professionals or experts set the rules. We see this in social services commissioning structures, and also in health services and hospitals; we also see institutionalisation in universities, where those in positions of power develop university processes which favour academic ‘excellence’ and which do not recognise the full diversity of contributions which can be made by disabled people. Even those in the TV industry spoke of ‘institutionalisation’ when they recounted how programmes are commissioned, written and cast.

However, all those practices also involve people other than the ‘experts’. They are practices in which health or social care services are delivered to lay people, or in which academic credentials are delivered to learners. Thus each practice involves a set of people who are the ‘experts’ and another set of people who are the ‘recipients’. Even practices which are intended to be more equal and less divisive can easily become institutionalised in this sense, as we saw in dementia services or even sometimes with community supports for people with learning disabilities.

An obvious first step in challenging institutionalisation is to change the main social actors in the practice: thus we found in dementia practices that it makes a big difference if people with dementia themselves are leading activities or interactions with others. We also see how important it is for disabled people to be in positions of power in Health and Social Care services, and as senior academics in universities.

- **Disabled people need to be valued and respected**

We set out in this research to explore disabled people’s own solutions and to understand the relationship between co-production and change. Our second theme therefore is that change will only happen when practices themselves are shaped in new ways, so that value is given to disabled people who are involved in that practice. We know when someone with a disability has really received ‘respect’ because their contribution is something that is sought after, that changes the mainstream, and that develops the practice in a new direction. This was the premise in the parents’ strand of the research in Section 8, where the respect and value afforded to parents with learning difficulties meant that they changed the face of parenting support. Disabled people should not just be ‘allowed in’ to existing practices, but can be innovators and change-makers.

Would this change our idea about expertise? In health services, patients naturally would look towards medical expertise and want that to be brought to bear to solve their health problems. Therefore, we are not saying that all disabled people can solve their own problems, any more than other citizens can. However, we saw how deep level change could happen in the performing arts, where disabled performers (musicians or TV actors in Sections 3 and 4.) could bring new methods and ideas to the way things get done. Instead of sticking to scripted performances, for instance, the idea of ‘improvisation’ links with an honest approach based on individual personality, which can create new ways of doing music or stage performance.

Co-production was not a panacea, and in Section 9 of this report, we saw how the term could be used as a mere box-ticking exercise in some areas. That was also true to a large extent in the university sector. We were also aware that disabled people generally want to get on with their lives, their jobs and their own goals, rather than always having to spearhead change. For deep level changes to happen, the practices of co-production itself need to be shifted, so that more informality, relaxing of rules and equality of power can occur.

- **Everything that is done could be done in a different way**

Every time something is done, that is a new 'statement' of the particular practice; for instance, the ways in which PAs work with people with learning disabilities are very varied, because each person is different. Communication with people with dementia is also bound to relate specifically to the needs, personality and also the context of the conversation. It is easy to endorse the principle of individualisation, for instance creating policies that champion personalisation of services in social and health care. However, when these are put into practice, we often see how there is at best a 'reasonable adjustment' made to an existing practice, rather than a complete rethink. The point to emphasise here is thus that we all need to be creative, and to step back from the way things are 'normally done', realising that we could do things differently, just as the professionals in Section 8 of this report had done in supporting parents with learning difficulties. Culture, history and sometimes market-driven forces create social practices, which do not have to be our masters. For instance, universities can promote academic learning by becoming less driven by individual achievement, and move more towards the valuing of team approaches to learning, teaching and research. Personal assistance for people with learning disabilities can be re-shaped to give people a chance to develop their own thinking and decision-making, and support for parents with learning difficulties can be done in non-judgemental ways that value what these parents have to offer.

- **Social practices**

If there is one set of theories that has dominated our research, it is the ideas about social practices as developed by Elizabeth Shove and her associates. The understanding of practices as constituted by different types of 'elements' was extremely useful throughout this report, in helping to get a handle on the practices we were analysing, such as the parenting support in Section 8. Therefore, a starting point to challenge existing practices is to understand how they are built of a) meanings and values; b) the competences of human actors; c) material resources. None of these elements are static, and they all change over time.

Our research has brought new insights by focusing on the ways in which certain social actors (disabled people) can be excluded at times from practices in which most people participate easily. By seeing social practices through the lens of disabled people's participation, we are offered a

new type of focus to see afresh what is often taken for granted. In this we build on social practice theorisation of power (Watson, 2017) in which we can start to appreciate how one practice (for instance commissioning a TV programme or a social care service) can create a power structure which affects participation in practices which might take place in a different time and place (for instance within disabled people's organisations). Power can be transmitted via these connections, and our research has shown how important it is to understand that wider picture. Above all, we have highlighted in this report that the connections between practices matter. A patient going into hospital needs to have transport practices which work for him or her and which connect with the hospital practices themselves; a PA accompanying a person with learning disabilities into a shop is reliant on the vast array of market-driven choices on offer in a supermarket; a young disabled musician needs to have teaching assistants who can operate technology when it breaks down. All of these and many more instances create networks of practices, which might in themselves be sufficient, but which also need to connect and interact efficiently with other practices.

Therefore, we would claim that this type of disability study can support critical analysis of social practices, offering insights to social theory and social science research. For instance, instead of accepting that common activities like shopping, cooking or quiz nights simply exist, we can start to query them and to see that they could be done in different ways. Sometimes a shift of material resources moves things on, accompanied maybe by a change in the competences of the social actors. At other times though it is the shift of meanings which will change the practice, as more disabled people are enabled to take part – for instance in music making, visual arts such as pottery, or in the media. Nowhere is this more true than in co-production itself, where the value afforded to disabled people's input and insights is key to a shift towards deep-level changes in institutionalised practices.

- **Language matters**

One of the objectives of 'Getting Things Changed' was to discuss and connect micro and macro theories of social practice. The first strands of our research examined in detail the ways in which social interactions played out, in verbal and non-verbal encounters between disabled people and others. One of the ways of looking at practices is to zoom in at that level, to see how the ordinary resources of conversation may help us to

understand in detail how disabled people can become excluded or shut out from conversation in their everyday lives. Via the videos created by co-production groups in the Dementia and Learning Disability strand, we explored how this approach could translate the findings of a micro-analysis into change at practitioner level. However, those changes tended to stay at practitioner level (in the sense of professional practitioners). Identifying a social practice like for instance quizzing in dementia groups helped us to see how social practice theory could help us to suggest ways of re-shaping the practice as a whole. This connected for us the interactional elements of the practice (for example, questioning) with the wider resources and value attached to the social practice of quizzing. For instance, positive change might entail staff members ceding their powerful positions, trusting people with dementia to run their own activity. Quizzes could also be done differently with different material resources, such as more homely or relaxing environments.

The micro level of interaction connects with wider contemporary ideas about social practice theories. We felt that connection was potentially very significant, as research using Conversation Analysis is far more technically advanced than Social Practice Theories; we have a growing detailed understanding of social interaction, on which the researcher can build (Sidnell and Stivers, 2014). There were also links for us between social practices which could be observed ethnographically, and critical discursive approaches such as that of Fairclough (1993). As we went through the research, we saw more examples of how language threads through and defines social practices more generally. For instance, in universities, exclusionary practices can be justified by words such as 'We treat disabled students equally', or 'This building cannot be adapted because it is too old or beautiful'. Nearly all the practices we examined included elements of conversation or interaction (such as the interactions of doctors with patients in a hospital), and many were defined by words which had acquired specific power in shaping how things got done, such as 'excellence' (in universities), 'child protection' (during parenting support), 'technical musicality' (in music education) or 'austerity' (in social care). Each of these was used in specific contexts to limit or define the practices which took place. In order to create change, therefore, we sometimes needed to unpick the words used to justify or create the practice.

#### • **Could practices be changed by the law?**

Our findings about social practices might seem at odds with Human Rights frameworks such as the UNCRPD (Convention on the Rights of Persons with Disabilities) and the section 20 of the Equality Act 2010. That was the starting point of this report, along with the concept of 'reasonable adjustments' as enshrined in the Equality Act 2010, as it is conceived in human rights legislation. Laws can change practices, and there is no doubt for instance that everyday practices such as driving have been changed by laws about road safety or car drivers' responsibilities. Using the law has to garner support has also changed the way that parenting support operates for parents with learning difficulties in Section 8. However, there is a notorious gap between both the letter and the intention of human rights legislation and its impact on the actual lives of disabled people, as became evident in the 2016 UN report on the UK's progress towards human rights. We would argue that this gap is almost bound to exist if we only conceive of human rights as belonging to the individual.

In this research, we were happy to be able to focus on positive changes, and to try to understand better how these had worked – in hospitals, parenting services, music, universities and social care supports for people with learning disabilities. There were many positives which allowed us to unpack the way in which change can happen. However, we have also seen many examples of practices which systematically exclude disabled people, as they were simply not shaped with their needs in mind. That unfortunately still included aspects of the physical environment (with step access to buildings in the university, and inaccessible car parks in hospitals). More fundamentally, it included practices which were driven by the need to do things fast, to do things with minimum cost, or to make profit. In order to change those practices, we have to set our sights at a wide angle, to consider the political and economic forces which create those incentives. Inclusive practices which are 'universal' are not just about changing existing ways of doing things when one disabled person comes along. They are about reshaping the way things are done, so that disability is viewed as one valued aspect of human diversity.

When disabled people know that they can get through the door, both literally and metaphorically, then they can start to have a stronger voice, and to be part of the shaping of more inclusive practices.

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