

Getting Things Changed

Final Report: Reasonably Adjusting Hospital Services



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Summary

All hospitals have a standard way of ‘doing things’, which may influence how we think and behave. For disabled people, the lack of flexibility regarding how things are typically ‘done’ in hospitals may mean that they encounter problems in accessing good quality health care.

In this project, we explored the ways that hospitals in England made changes to their services, known as ‘reasonable adjustments’, to support disabled people. We were interested in understanding and sharing examples of where hospitals provided reasonable adjustments, but also how services could potentially be improved to better support disabled people accessing hospital care.

Overall, we found that the hospital provision of reasonable adjustments was patchy. On the one hand, several hospital professionals explained how they provided reasonable adjustments to support disabled people’s individual needs. On the other hand, our evidence highlights that such good practice was not routinely embedded within hospitals, and many disabled people experienced difficulties in accessing reasonable adjustments to meet their needs when attending hospital.



Project Overview

The Equality Act 2010 requires all public services in the UK to make changes to their services to ensure that disabled people are not disadvantaged. These changes are called 'reasonable adjustments'. The Equality Act 2010 defines a disabled person as anyone who has 'a physical or mental impairment' and for whom the impairment has 'a substantial and long-term adverse effect on [their] ability to carry out normal day-to-day activities'.

Within health services, the provision of reasonable adjustments is required for disabled people to be able to access care on an equal basis with non-disabled people. It is important to note the provision of reasonable adjustments is different from the provision of good quality health care. Good quality health care is care that everyone should expect to receive, regardless of whether they are disabled or not, for example, being comfortable, warm and safe (Care Quality Commission, 2017). Reasonable adjustments are the additional measures taken to ensure that disabled people are able to access good quality health care on the same basis as non-disabled people.

Public services must make reasonable adjustments in the following ways:

1. **Changes to the way things are done** that make it more difficult for disabled people to access care. In a health care context this could mean changing the location of a person's appointment, or offering a longer appointment with a doctor.
2. **Changes to a physical feature** so that it is easier for a disabled person to access or use it, such as making buildings wheelchair accessible.
3. **Provision of extra aids or services** that might help a disabled person to access a service, such as ensuring that an interpreter is present at an appointment or that information is provided accessible formats.

Service providers must consider reasonable adjustments that are anticipatory and responsive. Anticipatory adjustments are where service providers take pre-emptive steps to plan for and put into place reasonable adjustments that may be required by groups of disabled people, for example, ensuring that a service location is wheelchair accessible. Responsive reasonable adjustments are individually tailored for disabled people following processes of **Identification** of a disabled person's needs informally, such as by a doctor asking them about their needs, or by the disabled patient themselves sharing this information; or **flagging** a disabled person's needs by formally recording them on hospital systems, such as by an electronic 'flag' on a patient's record (Tuffrey-Wijne et al., 2013).

Although the Equality Act 2010 is in place to support disabled people in having reasonable adjustments made to their health care, evidence suggests that reasonable adjustments may not be effectively or consistently provided for all disabled people.

What we did and found in this project

The focus of this project was to gain an understanding about how reasonable adjustments are provided for disabled people accessing hospital care. To do this, we undertook five separate, but interconnected aspects of research:

1. An audit of CQC hospital inspection reports
2. An online survey to health professionals and Healthwatch representatives about how hospitals provide reasonable adjustments
3. Freedom of Information requests to hospital trusts
4. Interviews with disabled people about their own experiences of receiving reasonable adjustments to their hospital care
5. Workshops for health professionals and disabled people to share examples of how reasonable adjustments have been effectively provided to support disabled patients.

Overall, we collected data from those providing hospital care for disabled people, those with an awareness of health service provision, and disabled people with personal experience of hospital care.

Audit of CQC inspection reports

We reviewed 137 Care Quality Commission hospital inspection reports for hospitals with more than 50 beds. All reports were published in 2015 and 2016. The aim was to explore whether, and in what ways the provision of reasonable adjustments for disabled patients was mentioned.

We found that the majority of hospital inspection reports (84; 61%) did not make any reference to the term 'reasonable adjustments'. Reports that used this terminology often provided sparing descriptions as to how care practices were reasonably adjusted, so it was difficult to accurately determine the types of reasonable adjustments that were mentioned.

Nevertheless, the majority of inspection reports (132; 96%) did mention examples of care that might be considered reasonable adjustments. The most commonly reported examples included hospitals demonstrating evidence of flagging the needs of disabled patients; the use of a hospital 'passport'; the provision of accessible information, or alternative methods of communication; the involvement of a learning disability and/or dementia specialist, such as a liaison nurse or champion; and support for carers to support a disabled person in hospital. Examples of poor reasonably adjusted care were less likely to be included in CQC reports.

Online survey of health professionals and Healthwatch representatives

We sought to understand and report the views of hospital staff and Healthwatch representatives about current provisions of reasonable adjustments for disabled people in hospitals in England.

The survey asked respondents to think about one hospital – this could be a hospital they were employed at, or one that they were familiar with, and to consider: a) whether they had received any training or support in terms of the provision of reasonable adjustments for disabled people; b) whether the hospital had any methods of identifying disabled people requiring reasonable adjustments; c) examples of ‘anticipatory’ reasonable adjustments, and individually-tailored reasonable adjustments the hospital provided for disabled people; and d) whether the hospital created publicly accessible audits documenting these reasonable adjustments.

A total of 52 people completed an online survey (41 hospital staff involved with patient experience, and 11 representatives from Healthwatch). 90% (n=47) of participants (40 hospital staff involved with patient experience,

and 7 representatives from Healthwatch) had received some form or forms of training or support. 85% (n=44) of participants (37 hospital staff involved with patient experience, and 7 representatives from Healthwatch) were aware of ways that the hospital identified disabled people requiring reasonable adjustments. Participants also described how the hospitals ensured that reasonable adjustments were provided in a number of ways, such as: ensuring an accessible environment for people with physical or sensory impairments; providing modifications to appointments; and ensuring that hospital passports were being used effectively. Almost half, 46% (n=24) of participants (23 hospital staff involved with patient experience, and 1 representative from Healthwatch) felt that the hospital was auditing the provision of reasonable adjustments, although no participants were able to demonstrate that these audits were publicly accessible.

Freedom of Information requests to hospital trusts in England

We were interested in understanding the extent to which hospital trusts were meeting their obligations to support the health care needs of patients with learning disabilities. To do this, we used the Monitor criteria (2015), which were in place at the time, and which set six expectations for hospital Trusts providing care for people with learning disabilities. Two of the six Monitor criteria were particularly important for provision of reasonable adjustments: i) that hospital Trusts could correctly identify and flag people with learning disabilities to ensure that they received reasonable adjustments to their health care; and ii) that hospital Trusts had provisions in place to audit their support for people with learning disabilities, and that they made this information publicly available as reports.

In early 2016, we sent Freedom of Information requests to 141 hospital Trusts in England asking them i) to confirm the number of patients with learning disabilities using inpatient, outpatient and Accident and Emergency (A&E) services and ii) for details of publicly available audit reports.

A total of 132/141 (94%) of hospital Trusts provided information about the number of patients with learning disabilities using their services. Of these, 112 Trusts (85%) provided the number of patients with learning disabilities accessing inpatient services; 83 Trusts (63%) provided the number of patients with learning disabilities accessing outpatient services; and 88 Trusts (67%) provided the number of patients with learning disabilities accessing A&E.

A total of 125/141 (89%) hospital Trusts provided information about whether audit reports relating to the provision of reasonable adjustments for people with learning disabilities were available. Approximately half (51%; n=64) of the responding Trusts stating that they did not complete audits of their services for people with learning disabilities, or that they did not make this information available publicly.

Interviews with disabled people

We were interested in hearing and understanding disabled people's own experiences of receiving reasonable adjustments to their hospital care. We asked disabled people to describe one hospital experience from the last two years in the form of a 'journey', where they talked about what happened before they got to hospital, whilst they were at the hospital, and when they left hospital. The interviewees also described how they thought hospitals could potentially change or improve the provision of reasonable adjustments for disabled patients.

We conducted 21 interviews with disabled people from across England. The 21 interviews included 12 women, 8 men, and one disabled couple (man and wife). We did not ask disabled people to disclose the nature of their impairment during their interview, although many people did, and described physical, vision and hearing impairments, mental health conditions, and learning disabilities.

Overall, disabled people's experiences of accessing reasonable adjustments in hospitals were mixed, and there was evident confusion about what should be expected as good quality care, and what was reasonably adjusted care.

Identifying a disabled person's needs for reasonable adjustments:

When processes to identify or 'flag a disabled person's needs were in place, these were

reported to be often inconsistent, and to not necessarily translate into reasonable adjustments being provided. Many of the disabled interviewees described frustration at having to continually disclose their needs to different hospital staff.

Changes to the way things are done:

Interviewees provided several examples of how hospital staff had changed their approaches to ensure that the person's individual needs were met, such as ensuring that a disabled person could use their own wheelchair in hospital. However, disabled interviewees also spoke about how they sometimes had to align their own needs with what was typically 'done' within hospitals, such as having to undergo hospital procedures that were not designed or adjusted to accommodate their impairments.

Changes to a physical feature:

Disabled interviewees provided examples of how hospitals had been designed in accessible ways, such as enabling physical access and in the visual appearance of corridors and wards. However, disabled people also described how accessibility was often variable, such as through wards or corridors being inaccessible for wheelchairs.

Provision of extra aids or services:

Disabled people occasionally noted how additional support was put in place for them when accessing hospital care, for example the provision of information in an easy-read

format. Some disabled interviewees noted that transport was not suited to their needs because it was not wheelchair accessible, or because journey times or routes were inappropriate for their needs.

Recommendations for change: Disabled participants recommended four key areas for improvement in terms of how reasonable adjustments are provided by hospital services:

1. A broad change in how reasonable adjustments are viewed and enacted by hospital staff. Disabled interviewees wanted hospital staff to recognise that all disabled people have specific needs,

and to understand why reasonable adjustments are important. In particular, disabled interviewees felt that staff needed training about the needs of disabled patients, and the provision of reasonable adjustments for disabled people.

2. Improving how hospitals identified and 'flagged' the needs of disabled patients.
3. Improving the general accessibility of the hospital environment, such as making changes to the physical access of buildings, or ensuring that the Accessible Information Standard (NHS England, 2017) is adhered to.
4. Ensuring that disabled people are fully involved in making positive change happen.

Workshops for health professionals and disabled people

We held four workshops for health professionals and disabled people, to share and discuss examples of good practice in relation to the provision of reasonable adjustments for disabled people.

One workshop was held in Bristol and one in Leeds in March and April 2017, and then again in October 2017. The workshops evidenced that many hospital staff were enacting excellent examples of reasonably adjusted care at a collective level (e.g. a care pathway for people with learning disabilities accessing hospital care that ensures consideration of the provision of reasonable adjustments) and in relation to the specific needs of disabled individuals. Discussions at the workshops indicated that the keys to

effectively providing reasonable adjustments were:

1. Being able to effectively identify groups of patients who may be disadvantaged when accessing hospital care. For example, this might be all disabled people, or disabled people from a particular geographical area, or who have a specific impairment.
2. Understanding why these groups are disadvantaged and what can be done to address this, so that effective reasonable adjustments can be introduced and embedded.
3. Ensuring effective collaboration and co-ordination between health professionals and others to ensure that the strategies to introduce and embed reasonable adjustments can be successful.

Project summary

Bringing the findings from all five stages together, our project has revealed a mixed picture about how effectively hospitals are providing reasonable adjustments for disabled people. Many hospital professionals have shared how they are providing effective reasonable adjustments to support disabled people, through their responses to the online survey or their participation at the workshops. Individual disabled people's stories during the interviews described some examples of how reasonable adjustments were provided to effectively support their needs. However, these reasonable adjustments did not appear to be consistently enacted and embedded within hospital practice. Disabled people's experiences highlighted examples of where they had not received effective reasonable adjustments to their hospital care. Freedom of Information responses suggested that hospitals were not easily able to identify people with learning disabilities using their services; nor were hospitals easily able to share publicly accessible audit reports that provided reassurance about the provision of reasonable adjustments. How the provision of reasonable adjustments was perceived and reported in CQC inspection reports was unclear.

In order to improve how disabled people receive reasonable adjustments to their care in hospital, we first need to consider, and reflect on, how hospital services are used from the perspectives of patients and professionals. Every hospital creates a culture or typical 'way of doing things', which shapes both disabled people's experiences as patients, but also how hospital professionals work with their patients and other colleagues. It is these standard ways of 'doing things' within hospitals that potentially disadvantage disabled people, because they generally situate disabled people outside of the norm. It is only when hospital 'ways of doing things' include and accommodate the needs of disabled people that the successful consideration of reasonable adjustments is made. Thus, our findings suggest that until the provision of reasonable adjustments becomes a part of the mainstream activities of a hospital and embedded into routine systems and processes, disabled people may continue to be disadvantaged.

Policy and practice recommendations

NHS Improvement

Clearer guidance is needed for hospital managers about what reasonable adjustments are, and the obligations of hospital services to provide reasonable adjustments for disabled people

Guidance needs to be such that it supports greater consistency in the provision of reasonable adjustments, clarity for staff about their roles and responsibilities, and clarity for disabled people about what they could expect to receive.

Care Quality Commission

The CQC should develop a standardised way of assessing and documenting the reasonable adjustments provided by services for disabled people

The CQC assesses the responsiveness of providers to those using their services. A focus on the responsiveness of services to meet disabled people's needs would be timely.

Commissioners

Policies and practices regarding the adequate provision of reasonable adjustments for disabled people should be regularly reviewed and audited

Commissioners should ensure that contracted services are operating within the legal framework of the Equality Act 2010. Our Freedom of Information requests indicated

that hospital trusts were rarely able to provide evidence of audit reports that provided assurance that the needs of disabled patients were met. Routine audits should be required, and the findings of such audits publicly available in accessible formats for disabled people and other interested stakeholders.

Hospital trusts

The provision of reasonable adjustments for hospital patients requires strengthening at the local level

The Equality Act 2010 describes the national policy framework for the provision of reasonable adjustments, but operationalising this at local level requires specific local policy, developed in conjunction with disabled people. Such a local policy should describe arrangements for the identification, recording and provision of reasonable adjustments for disabled people, so that hospital staffs are clear about their roles and responsibilities.

Consistent and routine identification and flagging is required of the needs of disabled people for reasonable adjustments to their care

Many hospitals identify and 'flag' particular individuals or groups of disabled people, but this does not appear to be consistent. 'Flags' should record a patient's eligibility for reasonable adjustments under the Equality Act 2010, and clarify the adjustments agreed to be in place by the service provider.

Staff training about the provision of reasonable adjustments requires review and strengthening

The research identified significant variation in the degree to which hospital staff appeared to understand the Equality Act 2010 and its requirement for the provision of reasonable adjustments for all disabled people. We noted that staff sometimes viewed their obligations as being relevant only to people with learning disabilities, and not all disabled people.

Training, which could helpfully be designed and co-delivered with disabled people should provide a comprehensive overview of the responsibilities of all hospital staff, and be relevant to all disabled people. The focus “always listen – never assume” should be adopted.

The Accessible Information Standard requires better implementation

We have identified variable understanding and adherence to the Accessible Information Standard by hospital professionals. We recommend that hospital trusts review staff understanding of how they provide accessible information to patients, and make any changes in practice as necessary.

Hospital policies should provide staff with the authority and resources necessary to provide reasonable adjustments

In order to support positive change in how reasonable adjustments are provided within hospitals, clarity and flexibility is required about how members of staff are able to respond to the needs of disabled patients.

Local policies about the provision of reasonable adjustments should be communicated to disabled people

Disabled people need to be informed about how their needs for reasonable adjustments will be identified, recorded and provided.

Disabled people themselves advocate the development of standardised information to be included as a leaflet within appointment letters, and displayed in patient areas of the hospital.

System-level adjustments for groups of disabled people require auditing in conjunction with disabled people

Our evidence suggests that many hospital services are physically inaccessible for disabled people to use, for example, inaccessible corridors and wards for people with physical and sensory impairments, or ambulance services that are not wheelchair accessible. In conjunction with disabled people themselves, hospital trusts should audit the accessibility of their environments for disabled people, and make necessary changes.

Disabled patients and staff should be views as assets to the organisation

The experiences of disabled patients and staff can be used to stimulate powerful and positive change in how reasonable adjustments are provided within hospitals. In other words, disabled patients and staff are not just simply ‘users’ of hospital services, their unique experiences and insights as disabled people can provide non-disabled people with new and potentially challenging perspective about engaging with, and using hospital services. We strongly recommend

that disabled patients and staff should to be included within all decisions that may potentially influence their future experiences.

Health professionals

The provision of reasonable adjustments is everyone's responsibility but coordination is required

Although the provision of reasonable adjustments is everyone's responsibility, the importance of effective communication and coordination by staff when supporting disabled people cannot be over-estimated. Disabled people reported great frustration at having to repeatedly report their needs to different members of hospital staff and said they would value having a named contact for their care with whom they could liaise about their particular needs.

There needs to be effective communication between staff and disabled people about their individual needs

Effective communication requires hospital staff to communicate with disabled people in ways that are accessible to them. One size does not fit all. Standard processes such as calling a patient's name in the waiting area, or relying on screen-based information must be adjusted as necessary to meet the needs of those for whom this is not appropriate.

Processes need to be in place to review the reasonable adjustments required by disabled patients

Discussing and reviewing agreed reasonable adjustments for disabled patients should take place on a regular basis to ensure that they are being provided as appropriate, and kept relevant and up-to-date.

Practitioners should share examples of reasonable adjustments to encourage and motivate others to understand what is possible

Several interesting and creative examples of the provision of reasonable adjustments were shared with the research team, but had not been shared more widely. These, as others like them, could act as incentives to other practitioners, who could learn from the strategies, successes and challenges experienced by hospital staff in delivering reasonable adjustments for disabled people. Creating a 'Reasonable Adjustments Database', or other internal ways of recording and sharing examples of reasonable adjustments (within and external to the Trust), would be helpful.

'Take home' messages for hospital professionals

1. The Equality Act 2010 requires that disabled people should have reasonable adjustments made to their care so that they are not disadvantaged in accessing health services.
2. Disability comes in many forms – and some disabled people may not necessarily identify themselves as disabled. Sensitive questioning as part of person-centred care about the specific needs of individuals may be required to identify disabled people and any needs for reasonable adjustments to services.
3. It is the responsibility of all staff, clinical and non-clinical, to ensure that disabled people can access health services on a par with non-disabled people.
4. All patients should expect to receive good quality care; disabled people may require the provision of reasonable adjustments to do so.
5. Agreed reasonable adjustments need to be clearly recorded in patient notes and the information easily accessible to the healthcare team.
6. Sharing examples of how care has been adjusted for disabled patients is helpful for developing good practice across service areas.
7. The value and importance of providing effective reasonable adjustments extends beyond disabled people themselves. Not only will the provision of effective reasonable adjustments enhance a disabled person's access to care, but they can also promote a more positive patient-professional relationship, lead to improved efficiency, fewer delays in treatment, fewer missed appointments, and shorter stays in hospital.
8. Disabled people should be involved in shaping and reviewing how reasonable adjustments are provided by hospital staff.

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