Disability Rights Commission

Learning lessons: Defining, representing and measuring disability

Contents

Executive summary

The Disability Rights Commission's (DRC) 'learning narratives' project is part of the broader legacy strategy of the DRC. It sets out what the DRC has learnt through its various activities since 2000 and focuses on specific activities or over-arching themes.

Each narrative responds to questions such as 'why did we, the DRC, try to do what we did?', 'what worked?' and 'what didn't work and why?' and draws on a range of data sources, not least of which is the experience and expertise of DRC staff.

This narrative considers what 'disability' is, who 'disabled people' are and looks at some of the implications these considerations presented to the DRC as it sought to communicate with and about disabled people and to create an environment in which disability equality was seen as an important goal for public policy and public services, for the benefit of the whole of society.

Introduction

A fundamental challenge that the DRC faced is the various ways in which disability is defined and discussed. This narrative considers what 'disability' is, who 'disabled people' are and examines some of the implications these considerations presented to the DRC as it sought both to communicate with and about disabled people and to create an environment in which disability equality was seen as an important goal for public policy and public services, for the benefit of the whole of society.

What is 'disability' and who are 'disabled people'? The challenges for the DRC

One of the major challenges facing the DRC from the outset was the existence of multiple definitions of disability – in research circles, among disability activists, and among the wider public.

Different definitions of disability were used by various big national surveys, giving different overall figures for the numbers of 'disabled people' in Great Britain. For example, some surveys used concepts to do with a condition that was limiting in terms of the labour market, whilst others asked complex questions that listed different types of impairment. Others simply asked 'are you disabled?'

The articulation of a 'social model of disability' in the 1980s, defining disability as the product of the interaction between a disabling environment and people with impairments, gave shape to a strong movement of 'disabled people': activists with a strong political and group identity across impairment lines.

However some people, including some defining themselves as Deaf or as users of mental health services, did not feel that the term 'disabled person' and the discourse of 'disability rights' was sufficiently relevant to embrace them to the exclusion of those other identities. There had also been critiques of the social model from the perspective of gender and ethnic or cultural identities.

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In addition, associations with the term 'disabled people' in public discourse appeared to be at odds with a social model approach: first, by being limited largely to those with significant levels of (mostly) physical impairment; and, second, by still defining disability solely as the immutable product of an impairment and therefore as something to be pitied and, wherever possible, cured. Where there were references to '11 million disabled people' in Britain, this figure was greeted with cynicism ('I hardly ever see anyone in a wheelchair'), as overstatement by campaigners simply demanding more from the public purse.

Multiple definitions of disability used internally and externally

This multiplicity of meanings for terms such as 'disabled people' and 'disability' was mirrored within the DRC. When talking about its primary stakeholders, 'disabled people', who was actually being talked about? Who were the beneficiaries? Who did the DRC need to talk to and about what? How big an issue was disability in Britain?

At the start at the DRC, different definitions of disability were being used: for example, the way that the DRC's Helpline classified 'disabled people' was different to that of the human resources team.

Even at a corporate level, the DRC needed to find a way to ensure that a consistent approach was taken. So, within a few years, the DRC created a standard procedure for monitoring disability, to be used by all DRC functions.

With a common corporate procedure, every function within the DRC was able to use the same method of measuring and recording 'disabled people', which had the benefit of strengthening the DRC's position and making it more credible.

The challenge facing the DRC of defining disability for corporate purposes was, however, simply a microcosm of the major external challenge of confusion about what disability means and the resulting challenges in terms of changing behaviour or public policy. Important national surveys, such as the Labour Force Survey and the Family Resources Survey, used different definitions of disability: sometimes using only one 'yes / no' question to ask whether someone was disabled and sometimes using (varying) lists of impairment groups.

After recognising the problems not just for itself but for government, business and other stakeholders presented by this situation, the DRC became a major player in securing the streamlining of disability questions used in surveys and pushed for disability to be covered in the 2011 Census.

Securing a disability question in the Census was felt to be extremely important, as it was likely to lead to streamlining and consistency across the various national surveys that included disability.

The DRC worked with the Office for National Statistics, the Office for Disability Issues and the Department for Work and Pensions to try to ensure that a disability question was included in the next Census. At the time of writing, it was not certain that this would be a question that provided sufficient detail to be valuable (cf. questions on religion).

'Disabled people': not a homogenous or static group

The DRC adopted the social model of disability as a principle and this was clearly important in defining what the DRC was: a change agent, using the law and persuasion to tackle discrimination and disadvantage; to change behaviour; and to influence public policy.

However, some of the ways of talking about disability that had developed as a result of the social model were overly reliant on 'insider knowledge' of just what it meant; some of the language bordered on jargon. Identifying people in terms of an impairment or health condition was frowned upon, for example, because of the historic medicalisation of many 'disabled people'. However, without any differentiation by the DRC between different groups of 'disabled people', whether on the basis of impairment type or other personal characteristics, there were a number of possible pitfalls.

First, in talking only about 'disabled people', there was a risk that a very diverse set of people in terms of experiences, age, ethnic or cultural heritage and impairment type would be seen as a homogeneous group by, for example, public and private sector service providers and employers and by government policy-makers.

In particular, research had shown that the prevailing association of the term 'disabled person' was with a wheelchair user. As a result, the view typically held was that by putting a ramp on a bus, transport would be made accessible for all disabled people. As recently as the 2006, the British Social Attitudes Survey[1] showed again that disability is still largely perceived in the narrow and outdated sense of visible physical disability.

By contrast, the Disability Discrimination Act covers a very broad group of people (estimated at one in five of the British population) – because discrimination can affect so many people. The definition includes people with long-term health conditions that are fluctuating and people who have been 'disabled' in the past, for example as a result of depression. Many of these people would not describe themselves, nor be

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1   NatCen (2007) British Social Attitudes Survey, 23rd Report.

considered according to 'common sense' definitions, as 'disabled people'.

Second, and linked to this public perception of who 'disabled people' are, was the risk that very many of the people who needed to know about and could benefit from the Disability Discrimination Act and the DRC would ignore it because they did not consider themselves to be 'disabled'. Additionally, employers and service providers would consider the 'job done' if they took action on physical access but would not invest time and thought, for example, in the types of adjustments that meant they could employ or retain someone with bi-polar disorder – 'the mental health equivalent of the ramp'.

Third, in terms of the strategy the DRC had adopted to 'narrow the gaps' of inequality, in its Strategic Plan of 2004-07, using the umbrella term 'disabled people' masked the differences that existed between groups of people who all had impairments but also had other particular characteristics.

So, for example, an overall employment rate of 50 per cent for 'disabled people' masked the fact that just 20 per cent of those with mental health conditions or learning disabilities were in work; and while the risk of child poverty among families that include a disabled adult was 36 per cent in white families, it rose to 83 per cent in Bangladeshi families.[2]

Without defining and measuring these differences, public policy would not be informed by them; solutions would not be sufficiently tailored to be effective; and improvements overall would mask continuing or worsening inequalities for some groups.

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2   Platt, L. (2006) 'Ethnicity and Child Poverty, Research for the Ethnic Minority Employment Task Force', data derived from Households Below Average Income statistics.

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Not acknowledging the heterogeneous and fluctuating nature of the group of people experiencing discrimination and disadvantage on grounds of impairment and health was also likely to undermine any sense of the wide relevance of 'disability rights' to Britain's economy and to social cohesion – and therefore its strategic and political importance.

The personal is political: reconciling an interest in personal characteristics and the social model of disability

Thus, the DRC acknowledged that it was important to ensure that it and others represented, portrayed and measured the different experiences of groups of 'disabled people' on various indices, such as the other equality concerns of gender, race, sexual orientation, age, religion and belief; broad type of impairment / health condition; other differentiating factors such as family circumstances or geography.

Both internally and with some stakeholders, the most contentious issue was of classifying people by impairment group, as this appeared to some to be in conflict with some expressions of the social model, which assert that impairment is irrelevant or should go unremarked. However, following internal debate on this issue, the importance of capturing impairment data when it is relevant to do so was acknowledged.

So, for example, the DRC's Disability Equality Duty monitoring guidance highlights the importance of public bodies recognising that: 'Differences in outcome reflect the fact that people with different impairments can experience particular types of barriers to equal participation.'[3]

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3   Disability Rights Commission, 'The Disability Equality Duty: Guidance on gathering and analysing evidence to inform action'.

The DRC's approach was therefore to recommend three questions – one about whether someone is 'disabled'; one about impairment or condition type; and one about barriers faced. The impairment question was framed as widely as possible, so as to maintain the balance between receiving sufficient information while not shifting too far towards a medical view of disability.

The premise was that in order to take action against discrimination, the experiences of different groups of disabled people in terms of impairment type need to be known, understood and monitored: for example, that people with mental health conditions are worse off in terms of employment rates than those with physical impairments.

These variations are also likely to include ethnicity, age and gender. As with noting ethnicity or age, noting impairment type did not imply that the existence of impairment in and of itself was the root cause of disadvantage. However, without this information, action to tackle discrimination and disadvantage was unlikely to be sufficiently targeted or affected.

Communicating disability: how do 'disabled people' think about themselves?

In 2002, research by the Department for Work and Pensions found that around half of the 11 million people classified as 'disabled' under the Disability Discrimination Act did not describe or want to think of themselves in that way.

The DRC wanted to find out more about why this was the case, to ensure that its communications with and about 'disabled people' were effective, including by ensuring that everyone who might need the protection of the DDA knew about it.

In 2004, the DRC therefore conducted its own research into what led people likely to meet the definition of disability in the DDA not to identify themselves as a 'disabled person'. The research was carried out as part of a broader programme which looked to support effective communication between the DRC and its various target audiences.

The DRC's research results

The research included focus groups and a survey of 1,000 people, all chosen on the basis that they were likely to meet the DDA definition but did not describe themselves as a 'disabled person'. It was weighted so that the proportions of different types of impairment mirrored those present among all 'disabled people' in Britain.

The research looked at this group's perceptions of what being 'disabled' meant, how they described themselves, the impact of impairments and health conditions on their daily life and their attitudes towards the DRC and rights.

The research found that there is still a substantial amount of stigma and fear about disability and that people did not choose the term 'disabled' because they associated it with someone who is most likely to be a wheelchair user, completely dependant on others and housebound.

Among the 1,000 people surveyed, the researchers segmented people into one of four groups, which they gave descriptive names:

- 'The Bothered' were most likely to have been recently diagnosed. The majority said that their condition had impacted a great deal upon their family and social life. All reported feeling frustrated and an overwhelming majority felt angry when told they could be considered 'disabled'.

- 'The Hiding' were more likely to have visible impairments and to have been treated unfairly because of their condition. Unlike many others, over two-thirds of people in this group tried to hide their

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condition. Just under half reported feeling embarrassed by it.

- 'The Dealing' were less likely to have learning disabilities or mental health problems than other respondents and to be male. The vast majority claimed that their condition had not had much of an impact upon their lives and described their condition as 'just one of those things'.

- 'The Unaffected' were most likely to have been diagnosed with a condition more than ten years ago. The people in this group vociferously disagreed with the idea that they 'had a disability' and the vast majority described their condition as 'just one of those things'.

Of all four groups, the Bothered and the Hiding were identified as being a communication priority for the DRC, due to their being the most likely groups to be responsive to the DRC's communications work, whilst knowing least about either the DRC or their rights.

The findings of this crucial piece of research were confirmed by DRC research with other audiences, such as small employers and line managers in the public sector. While the DRC found varying levels of knowledge about the DDA and who it covered, there was always a presumption towards disability relating to physical access and a consequent perception that disability was a 'niche' issue, of relevance to a relatively small group. This perception was one that we considered operated also at the level of media and public policy interest in disability issues: worthy but not newsworthy.

DRC Communication Strategy 2005-07

Basic communications theory holds that to be effective, methods should include detailed knowledge of the intended audience's attitudes and attributes and should be attuned to these. The DRC's research found that language that was condition-specific was the most appropriate way to make contact with people who were covered by the DDA but did not consider themselves 'disabled'. This was especially true for young people, who were found particularly likely to reject the 'disabled' label and instead saw themselves as someone with, for example, arthritis, cerebral palsy, depression, epilepsy, diabetes or dyslexia.

The research also found that talking about 'rights' and 'campaigning' was not the most effective way of communicating with such audiences. This language would confirm to these people that the DRC was not relevant to them. Instead, evidence suggested that the DRC should talk about 'fairness', 'support', 'help' and 'getting on with your life'.

In responding to the findings of this and related research, the DRC faced a substantial challenge: to talk about rights and equality issues in ways that acknowledged the reality that many 'disabled people' felt that their condition did have a major impact on their lives.

During debates on the communications strategy, the DRC's Commissioners decided to keep using 'disabled people' rather than adopt 'people with disabilities', which research indicated would have been preferable to many of our target audience. However, while the latter term would have helped the DRC to reach new groups of people less likely to know

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about their rights, it would have been offensive to many of the core stakeholders who had campaigned for anti-discrimination legislation in the 1980s and 1990s. A compromise was therefore necessary.

This challenge was tackled in a variety of approaches and is best summarised in the DRC's Communications Strategy for 2005-07. This involved moving away from only ever talking about 'disabled people' towards using, as relevant to the particular audience, such terms as 'people who are disabled or have long term health conditions' and 'people with rights under the DDA'. The DRC also stopped using '11 million disabled people in Britain' (one in five), recognising that without further explanation this was provoking disbelief and cynicism in parts of the media and more broadly.

Some DRC commissioners had strong views on the use of language and approaches specific to particular conditions. DRC communications staff met resistance, for example, from some commissioners who believed disability activists would perceive talking to people via health-related channels and altering language in some cases to reach different groups would be perceived as a return to a medical model approach.

At the same time, it was also felt that it would not be worth the time or money invested to produce communication materials that did not have the desired impact. Messages that failed to engage target audiences would leave thousands of people at risk and disempowered to act if they experienced discrimination.

As a result of research and gaining approval for a new communications strategy, the DRC was able substantially to increase awareness of various types of barriers and adjustment. While the DRC's Open 4 All campaign was focused on the changes in the law that related to physical access, the DRC also sought to balance this with

communications targeted at and about people with mental health conditions and learning disabilities.

Campaigns such as 'Are We Taking the Dis?' and our small employer campaign, the health inequalities formal investigation, promotion of legal cases and marketing work in pharmacies targeted at older people and those with invisible health conditions have all helped the DRC to raise awareness of the breadth and reach of 'disability'.

This approach has also fed into the DRC's public affairs work, notably in the Disability Agenda, where the DRC explicitly seeks to demonstrate how equality for 'disabled people' and their families could have an impact on the major public policy imperatives for Britain. These areas include: child poverty and family breakdown; the skills gap; full employment; safer communities; housing; and social care fit for the challenges of demographic change.

Did it work?

It is hard to draw conclusions on the basis of just a few years' work by the DRC about changes to public discourse and indeed in terms of the impact of the DRC's work programmes more broadly.

The DRC Opinion Former Survey of 2006 about the DRC showed a very favourable picture and a sense that the DRC had helped to put disability on the map – though there was still a sense that disability was not yet considered an important enough priority at national level.

At an operational level, the DRC's media strategy – of repositioning disability as not just worthy human interest but newsworthy and of political and policy significance – appeared in the last few years of the DRC's life to be bearing fruit. Coverage of DRC stories had moved from the local and regional press to more broadcast coverage and more coverage in national newspapers in the news and comment sections.

Concluding remarks

Arguably, the operation of the research and communications functions within the DRC influenced the organisation at a deeper strategic level too: in terms of how it has refined its core purpose as an agent of change. The DRC, when it ended its journey in 2007, was no longer working just to benefit a clearly defined and bounded group of 'disabled people' but was seeking to create an 'alternative future' where no one at any stage of life was judged or disadvantaged on grounds of health or disability and where disability equality was seen as an important goal for public policy and public services, for the benefit of the whole of society.