

hospital. They don't think we lead a full social life or even want to attempt to do so." On reliance on the use of print, "I don't see why I should have to have other people read my bills or letters." Deaf women have described difficulties in using health services, such as communication problems in opticians' and dentists' surgeries and in x ray departments, where rooms are dark, eyes are covered, or the staff are behind screens.¹¹

Addressing disability from the civil rights and social model perspectives is consistent with the public health approach of achieving improved health through organised efforts of society. Many disabled people are systematically excluded from aspects of life known to promote good health, such as education, employment, leisure, and exercise. But the disabling effects of society are not usually included in public health debates. A paper on the health implications of transport policies, for example, does not address the barriers disabled people face.¹² Travelling (to work, to the shops, for social events) is essential for full social inclusion. Walking and cycling are not options for everyone, and public transport is currently not fully accessible. This must be addressed when promoting healthy transport, or travel will become harder for disabled people, increasing their social exclusion.

Locating disability in society makes it easier to implement the Disability Discrimination Act because this approach avoids asking the wrong questions. Applying the medical model results in people being asked about their impairments. They respond by stating the name of their medical condition, but this says nothing about their barriers to access. Applying the social model results in questions about barriers, be these stairs, voice only telephones, or print.

Making services accessible means challenging the concept of what is normal and changing how services are provided. If organisations are to implement change successfully disabled people must contribute to its implementation⁷: they know best the barriers they face and can offer practical solutions.^{10 11} But barriers to full

participation must first be addressed. This means taking into account, for example, that some people use wheelchairs, some use visual languages, and some gain information from audiotape.

At a practical level, all health staff should know their responsibilities under the Disability Discrimination Act and understand the social model. Again, disabled people often identify inappropriate staff attitudes and behaviours as the biggest barrier to using health services.⁷ Can they be confident that they will be afforded equal access to health services if they are not also confident that the medical profession will not discriminate against them becoming doctors?

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One Bristol, but there could have been many

Radical change is essential but hard to achieve

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Some will read the well written report of the Bristol inquiry into children's heart surgery as a "whodunnit?"¹ The answer is that "the system done it," but various named individuals behaved dishonourably. Some have been struck off by the General Medical Council.² All will have paid a heavy price with sleepless nights. The report is primarily, as Ian Kennedy, the chairman, says in his introduction, a tragedy. A great many well intentioned people worked hard to do good but did dreadful harm. Over 30 children under 1 year died unnecessarily, the report concludes.³ Many more were severely injured.

The most chilling thought in the report is that there could have been 50, perhaps 500, even 5000 similar reports about other parts of the NHS. The ingredients that led to the excess deaths in Bristol occur throughout the NHS. The report emphasises not only that the NHS had no system for monitoring quality and no reliable

data but also there was no agreement on what constituted quality. "Thus the most essential tool in achieving, sustaining, and improving quality of care for the patient was lacking ... clinicians had to satisfy only *themselves* [the report's italics] that the service was of sufficient quality."⁷

Bristol (and we must accept, as does the inquiry, that Bristol has become a noun that denotes not just a city but also a medical tragedy) came to public attention because there were some data and people concerned to make a fuss. We might have read a report on excess deaths in a general medical unit in Barchester or wholly inadequate psychiatric care in Slagthorpe, but we won't because there were no data, nobody made a fuss, and the bodies are lost. It took decades to spot that Harold Shipman, a general practitioner near Manchester, had become Britain's most prolific serial killer, murdering perhaps 400 of his patients.⁴ The

BMJ 2001;323:179-80

government—despite acknowledging that “at present, there are unacceptable variations in the quality of care available to different NHS patients in different parts of the country”—is anxious to reassure the public that something like Bristol could not happen now. It’s false reassurance. The machinery it has created and is creating is not yet adequate to prevent such a tragedy—and perhaps never will be.

Some might like to depict Bristol as a story of wicked surgeons running amok, but the report shows that the story was more complicated. Consider this paragraph, which I’ve edited slightly by removing specific references to Bristol to show its universality:

Throughout the inquiry we heard evidence of underfunding, meaning that a gap had developed between the level of resources properly needed to meet the stated goals of the unit and the level actually available. There were constant shortages of trained nursing staff. The level of specialists was always below the level deemed appropriate by the relevant professional bodies. The consultants lacked junior support. They were expected to care for patients in places that were several hundred yards apart and to hold outreach clinics all over the region. Some facilities and necessary medical equipment had to be funded through the good offices of a charity.

This is the NHS throughout Britain in 2001, not just Bristol in the early 1990s. The report acknowledges that it was typical of the whole NHS and concludes, “whatever went wrong in Bristol was not *caused* [the report’s italics] by lack of resources.” The extra factors were poor teamwork and management, inadequate leadership, a closed “club” culture, an absence of systems to monitor performance, a failure at the centre to listen to concerns, and some “individuals who, in our view, could and should have behaved differently.” These factors too occur throughout the NHS.

It is this sort of analysis that leads many doctors in Bristol and elsewhere to believe not that everything was all right in Bristol but that the Bristol doctors have been scapegoated for the failures of a whole system. Ironically the report and now the government call for a “blame free culture” after an episode where three doctors have been demonised. “[These events],” says Janardan Dhasmana, one of the surgeons found guilty of serious professional misconduct, in the report, “have ruined me professionally, financially, my family life has gone and I have lost confidence in myself.” And doctors will not forget Frank Dobson, then secretary of state for health, setting aside the whole statutory process of the General Medical Council, and calling for Dhasmana to be struck off.²

I read the Bristol report as acknowledging that the whole NHS has failed to change with the times. Medicine has a long tradition of “muddling through” with inadequate resources. Doctors have been in charge and too busy to communicate; patients have been expected to be grateful, not demanding; safety has been forgotten and evidence ignored. Leadership and performance measures have been non-existent. Medical institutions have dined rather than reformed, and the government has concentrated on containing costs, changing structures, cutting waiting lists, and minimising fuss. “They [at the Department of Health] were not interested in results; they were interested in as many people passing through the system as possible for as low a cost as possible.”

One important message from the report is that children have had a particularly rough deal from the NHS. “Healthcare services for children are still, generally, fragmented and uncoordinated.” Children have been treated “as small adults, who simply need smaller beds and smaller portions of food.” As an article in the *BMJ* last year made clear,⁶ the service has failed to respond adequately to their special needs. Yet again, this report might equally have been about elderly, mentally ill, or learning disabled people or those from ethnic minorities. The NHS, despite its socialist roots, has performed poorly for the marginalised—or, to use the fashionable term, the “socially excluded.”⁷

A beauty of the Bristol report is that it paints a clear picture of what is needed. “The culture of the future must be a culture of safety and of quality; a culture of openness and accountability; a culture of public service; a culture in which collaborative teamwork is prized; and a culture of flexibility in which innovation can flourish in response to patients’ needs.” There must be steady increases in resources, good leadership, better systems of accountability, explicit standards of care, better management and communication, and public involvement at all levels. Above all, patients must be put first in deeds not words.

Who could disagree? But the report is less clear on how to reach this state of grace. It does recommend independence for the Commission on Health Improvement and the National Institute for Clinical Excellence and two new overarching bodies for them and the professional regulatory bodies. But then the report observes: “A plethora of organisations, all with their own ambitions and anxious to defend their ‘territories,’ was one of the defining features of what happened in Bristol.” The report makes 198 recommendations, most of which contain the verbs “must” and “should,” but declines to prioritise or cost them. “A further report, such as this one, with many recommendations,” they write, “might seem like the last straw [but] we believe that action needs to move forward in relation to all themes simultaneously.”

This is not good management. How do you move forward with 200 recommendations in an understaffed, under-resourced, demoralised organisation of over a million people? The answer is that we must, and that strong leadership is essential, but the scale of the task is breathtaking. The long term importance of Bristol may be not the particular events, the report, or even the proposed reforms but the tremendous kick it has given the NHS.⁸

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RS participated in a seminar organised by the Bristol inquiry.

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