

## Guest Editorial

# Disability Equality: Why Bother?

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At a time when a new scandal in Britain about unexpected deaths of disabled people, specifically, those with learning disabilities or mental health conditions, is attracting widespread attention, it might seem obvious that equality of disabled people is important in health and care services. As the Southern NHS Trust is held to account for investigating only 1% of unexpected deaths of people with learning disabilities, there is a new focus on the inequality of early death (Pym 2015). What, after all, could be more important than equality of health outcome – the simple right to have an equal chance to live to a ripe old age?

### Equal health outcomes

Sadly the evidence suggests life expectancy is far from equal between disabled and non-disabled people, even after accounting for disability-related factors, like suicide amongst mental health service users and early death from progressive conditions. The Disability Rights Commission (DRC) found, after analysing over 8 million primary care records, that people living with long-term mental health conditions were more likely to get killer diseases such as stroke, heart disease, some cancers and COPD, more likely to get them young, more likely to die of them quickly and yet less likely than their non-disabled counterparts to get the recommended screening, diagnostic checks and treatments. For instance, although more likely to experience stroke and heart disease, they were less likely to be prescribed statins. Part of the problem was ‘diagnostic overshadowing’: for example, clinicians assuming that palpitations were symptoms of anxiety and not heart disease; or that new sounds made by someone with a significant learning disability, without language, were just evidence of their challenging behaviour and not a sign of severe pain. Thus cancers and other major diseases get missed.

To this it may be argued that poor health outcomes cannot solely be laid at the door of health services. What about lifestyle? To be sure, smoking and poor diet play their part; but so do wider factors like social isolation. Disabled people are significantly more likely than non-disabled people to say they have seen no one, or only one or two people, in the last week (ONS 2015). Isolation is worse for your health than obesity, lack of exercise or excessive drinking and on a par with smoking (Holt-Lunstad *et al.* 2010). It damages many disabled people’s lives because they lack employment, social networks or simply the money to visit friends or buy a round in the pub. Or they see only health and care professionals – living, in effect, in a disability ‘ghetto’.

These disability-specific health inequalities deserve much greater attention than they usually receive. A commitment to physical health has now been built into English mental health and learning disability policy, prompted by the Disability Rights Commission’s (2006) investigation and campaigning by civil society organisations. Some commissioners of services are taking note but this commitment to physical health is new, and variably implemented.

‘I’ve just had a road to Damascus moment. I’ve often written and given presentations on health inequalities, focused on race and poverty, but I’ve just understood what a rough deal these other groups are having too’ (Professor David Haslam, Cited in DRC 2006)

### Diverse staffing

If there were ever a sector that could be expected to be good at employing disabled people, at understanding their potential, it is surely the health and social care sector. Organisations like NHS Employers, Disability Rights UK and others have worked to understand the barriers and range of solutions. Yet still people working in health services report cultures of ‘them’ (the patients) and ‘us’ (the staff) – with perceived risks if a staff member has the temerity (or courage) to be open about being both. As one person put it, ‘you don’t bleed when there are sharks about’.

Ensuring equal employment chances for disabled people is a simple matter of fairness. It also makes good business sense. Britain, like many countries, faces an unprecedented demand for care and health staff as the population continues to age: one way of meeting that demand is to tap into new labour markets. The British Government has an aspiration to halve the gap between the employment rates of disabled and non-disabled people so why not offer employment opportunities to disabled people currently out of work?

But there is a more profound reason for health and care organisations employing people with experience of living with disability or specific health conditions. They bring the expertise of lived experience (cf Perkins *et al.* 2010). Some organisations have deliberately employed peer support workers - staff who draw on their lived experience to share encouragement and knowledge with people trying to deal with the huge life change of acquired disability. If you have just had a spinal injury, there is nothing quite like talking to someone else who has already been through that experience – that loss of the life expected, that confusion and fear – to support you in your own journey. Peer support brings positive outcomes. A literature review by Repper and Carter (2011) found evidence that peer support workers in mental health services could lead to reduced admissions, an increased sense of independence and empowerment, higher self esteem, confidence, social connectedness and community integration.

It is not only designated peer support workers that bring value. Having staff at all levels who are open about their own lived experience changes cultures. It breaks down the ‘them’ and ‘us’ divide – and sees off the ‘sharks’. It shows that people living with challenges from bi-polar disorder to parkinsonism are contributors – not just ‘patients’. And as more people feel confident to be open about their own challenges at work, they lose the ‘big secret’ that consumes needless energy – and, in a genuinely inclusive workplace, gain in well-being, and

productivity. If cultures begin to change, to suit and support disabled people as citizens, as contributors – then that throws into sharp relief the whole purpose of health and care services.

### **A new purpose for health and support services**

Disabled people have long objected to clinical or ‘medical’ models of disability that box them into passive roles and make them feel as though the only hope on the horizon is cure. When cure is not forthcoming, hope is entirely destroyed.

The independent living movement, and the recovery movement in mental health, posit something very different: that hope rests on living a fulfilling life with your impairment or health condition; and that services should have, as their prime purpose, supporting you, on your own terms, to live the fulling life that you choose. This is reflected in some – albeit disruptive – medical writing, for instance Atul Gawande’s (2014) *Being Mortal*, in which he suggests asking people living with terminal conditions questions like ‘what is important to you?’ before suggesting options for treatment and support that might help meet their particular ambitions.

This approach requires a reconceptualization of the whole purpose of health and care services. Social care in this new context is no longer about ‘care’ of ‘vulnerable’ people but about enabling individuals to decide on the support that will best enable them to live the life they choose. Indeed ‘care’ in this context is an unhelpful word, with all its connotations of one giver, one passive recipient. The Equality and Human Rights Commission’s (2009) report *From Safety Net to Springboard* posits a very different approach, in which the disabled person is instead the agent in their own life.

Health services are no longer about cure for the many people living with long-term conditions or impairments or management of a condition, but about enabling people to manage their own conditions, receive and give mutual support with others, and choose the support from services that will best enable them to live the life they want.

This requires a very significant shift in health and social support cultures and organisations from providing expert services to patients or ‘vulnerable’ people, to enabling people to live the lives they choose; from prescribing treatments to enabling people to decide on their own priorities; from interactions between expert professionals and patients/clients, to interactions that share both lived experience and professional expertise.

### **Conclusion**

If ‘care’ became ‘support’ and health and support services

changed their mission, the prime purpose would be enabling citizenship participation. In other words these would be organisations promoting equality as their core mission.

Promoting equal health outcomes would be part of how they achieved this. Employing disabled people at all levels would be important to change cultures and model fairness. But ultimately what is needed is a new purpose for our health and support services: one that supports everyone living with long-term health conditions or disability to live as equal citizens, participating socially, civically and economically. Many organisations, including Disability Rights UK, work to support such transformations.

The answer to ‘why bother’ has far reaching implications for us all.

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