
Chapter 13

RIGHTS-BASED APPROACHES, PERSONAL BUDGETS AND LIVING BETTER WITH DEMENTIA

‘The philosopher and disability activist Judith Snow says: The gift of disability is the fact that the disabled person really needs help from another human.’

Simon Duffy, Tizard Memorial Lecture (4 March 2011)

Introduction

Under international law, the UN Convention on the Rights of Persons with Disabilities exists to protect citizens with disabilities. The Preamble begins:

The States Parties to the present Convention,

(a) Recalling the principles proclaimed in the Charter of the United Nations which recognize the inherent dignity and worth and the equal and inalienable rights of all members of the human family as the foundation of freedom, justice and peace in the world... (United Nations General Assembly, 2006)

The Equality Act 2010 in England and Wales makes discrimination against persons living with disabilities unlawful. Dementia is a disability. On 6 December 2014, the BBC news website ran an article entitled ‘Disabled people’s access to High Street “shocking”, audit finds’ (BBC News, 2014), which described discrimination against people living with disabilities. According to the report, accessibility experts DisabledGo visited all of the 30,000 venues in person to assess them, in the largest ever audit of its kind in the UK. They found one-fifth of shops had no wheelchair access, only 15% of restaurants and shops had hearing loops, and three-quarters of restaurants did not cater for those with visual impairments (BBC News, 2014). If we are shocked about this lack of access for people who are physically disabled, we should be equally shocked by the lack of accessibility for people with cognitive or behavioural problems as a result of living with dementia.

Swaffer (2014) compares the medical and the social responses to the event that is the disclosure of the dementia diagnosis:

Misguided and preconceived misconceptions about the symptoms of dementia are used to support telling us to give up living our pre-diagnosis lives. Instead, the recognition of the symptoms as disabilities would assist with a more equitable and dementia-friendly experience for the person with dementia after diagnosis. In contrast to the medical model, the disAbility model of care is positive and supports continued engagement with our prediagnosis lives.

The different ways in which a person might progress after a diagnosis are shown in Figure 13.1.

I introduced parity of esteem in Chapter 10 on whole-person care. For the sake of parity of esteem – in other words, not treating mental health as inferior to physical health – we need to apply the same rigour for ‘reasonable adjustments’ for cognitive or behavioural interventions as for physical ones. Equality law recognises that bringing about equality for disabled people may mean changing the way in which employment is structured, the removal of physical barriers and/or providing extra support for a disabled worker (see, for example, Equality and Human Rights Commission, 2014). Early dementia of the Alzheimer type is characterised by problems in learning and memory, including in spatial navigation (Serino and Riva, 2013). People with such cognitive disabilities will benefit from specialist design as a reasonable adjustment (Habell, 2013).

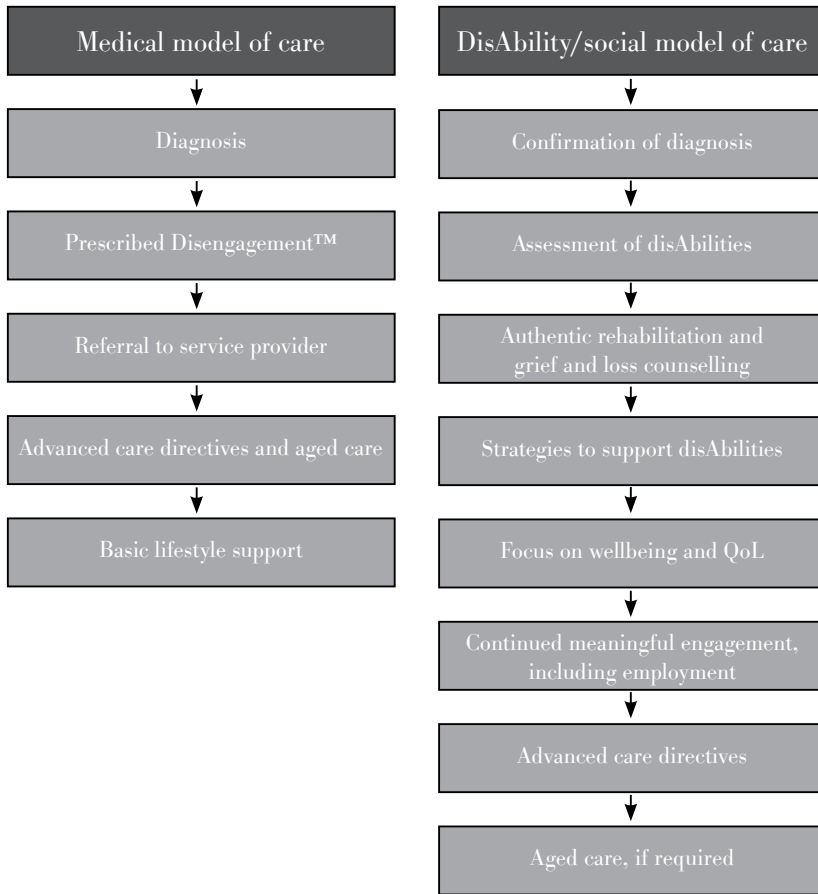


Figure 13.1 Medical vs DisAbility model

SOURCE: SWAFFER, 2014 (REPRODUCED BY KIND PERMISSION FROM KATE SWAFFER)

Promoting autonomy and dignity and the — Deprivation of Liberty Safeguards policy —

Promoting dignity for people trying to live better with dementia means a culture free from abuses of human rights, free from discrimination, and free from any other abuse. The Social Care Institute for Excellence (SCIE) Law Practice Guide 9 entitled ‘Promoting dignity within the law’ (2008) outlines the context in which dignity applies to health and social care. The philosophy is that human rights principles are very closely related to other principles of good professional practice, and share an ethical basis of concern with the autonomy, privacy and dignity of

people using services. And the law is continuing to evolve, both in the UK and abroad, at a very fast pace. The Care Act 2014 received Royal Assent (became law) in May 2014. This is the most significant reform of adult social care for more than 60 years, replacing a wide range of existing legislation with a single statute and introducing many new principles and procedures. For example, the introduction of the principle of the promotion of ‘wellbeing’ as the basis for any action or decision taken in relation to meeting someone’s social care needs, or for service planning.

Human rights law applies to all ‘public authorities’. No public authority must act in a way that is incompatible with human rights; ‘public authorities’ include local authorities and their staff, health boards and hospital staff, general practitioners, sheriffs, tribunals and others carrying out public functions (see, for example, Mental Welfare Commission for Scotland, n.d.). The human rights approach starts from the principle of human autonomy. I have discussed the notion of autonomy in some considerable detail, particularly in Chapter 9 of my book *Living Well with Dementia* (Rahman, 2014), in relation to advocacy, choice and control.

Deprivation of liberty should be ‘exceptional, objectively justified and of no longer duration than absolutely necessary’ (Macovei, 2002, p.6). The aim is to secure rights for individuals. Although a private care home is not a public authority (even though it may be providing care under contract to the local authority), Lady Hale in the House of Lords in *YL v Birmingham City Council and others* [2007] provided the key finding:

Given the approach of the Strasbourg court in *Storck v Germany* (2005) 43 EHRR 96, it is perhaps unlikely that the United Kingdom would be absolved from responsibility for deprivations of liberty taking place in private care homes. (Paragraph 70)

The Deprivation of Liberty Safeguards (DoLS) were intended to provide a level of protection to people who lacked capacity to make decisions about care and treatment. The safeguards are intended to protect people who lack mental capacity from being detained when this is not in their best interests, to prevent arbitrary detention, and to give people the right to challenge a decision. Whether someone has been deprived of their liberty depends on the particular circumstances of each case.

The safeguards apply to people in care environments including hospitals and care homes. Both self-funded and publicly funded residents are covered by the safeguards. The Code of Practice also includes a list of factors that have been taken

into account by the European Court of Human Rights and UK courts when deciding what amounts to deprivation of liberty.

These are only factors and not conclusive on their own. It will be a question of degree or intensity. It has been known for some time that the DoLS are fundamentally a human rights issue (Tingle, 2012). These safeguards were not, in fact, part of the original Mental Capacity Act in 2005. Introduced as amendments via the Mental Health Act 2007 in response to the findings of the European Court of Human Rights in the 'Bournewood case' and enacted in 2009, they are often seen as entirely separate from the rest of the Act. The European Court of Human Rights found that UK law did not give adequate protection to people who lacked mental capacity to consent to care or treatment, and who needed limits on their liberty to keep them safe. The change in the law introducing the Deprivation of Liberty Safeguards was necessary following the decision of the European Court of Human Rights in *HL v United Kingdom* (2004), concerning the deprivation of liberty of a man with autism and a profound learning disability. The Deprivation of Liberty Safeguards continue to attract much interest (Griffith, 2014).

At clause 254 of a recent House of Lords publication entitled 'Select Committee on the Mental Capacity Act 2005: Report of Session 2013–14 on Mental Capacity Act 2005: Post-Legislative Scrutiny' (2014), Toby Williamson of the Mental Health Foundation, and former co-chair of the Making Decisions Alliance, a campaign in support of the introduction of mental capacity legislation at the time the Act was passed, is reported as saying: 'We wanted a relatively simple legislative solution that met the requirements of the European court's findings on the case, something that reflected the elegant simplicity of the Mental Capacity Act.'

The recent law has added some clarity. The Supreme Court gave judgment on 19 March 2014 in two linked appeals: (1) *P v Cheshire West and Chester Council* and another; and (2) *P and Q v Surrey County Council* [2014] UKSC 19. Both appeals were brought by the Official Solicitor, who had acted as litigation friend for all of them. This case concerned the living arrangements of three adults without capacity to consent to their residence and care arrangements. The question was whether the arrangements amounted to a deprivation of liberty. Paragraph 45 of the judgment by Lady Hale is striking as it emphasises the universality of human rights. The judgment of *Storck v Germany* (2005) outlines the three tests of whether there has been a deprivation of liberty. Critically, section 64(5) of the Mental Capacity Act (2005) states: 'In this Act, references to deprivation of a person's liberty have the same meaning as in Article 5(1) of the Human Rights Convention.'

And reading the relevant clauses of the European Convention on Human Rights (ECHR) is indeed a helpful start:

Article 5: The right to liberty and security

1. Everyone has the right to liberty and security of person. No one shall be deprived of his liberty save in the following cases and in accordance with a procedure prescribed by law:

(a) the lawful detention of a person after conviction by a competent court;

...

(e) the lawful detention of persons for the prevention of the spreading of infectious diseases, of persons of unsound mind, alcoholics or drug addicts or vagrants...

While human rights law recognises that in certain specified situations (e.g. following the commission of a criminal offence) a person may be deprived of this right, this should only be for sufficiently weighty and pressing reasons, justifiable under the ECHR doctrines of 'necessity' and 'proportionality'. The legal doctrine of proportionality is pivotal to our law. Crucially, it states in Article 5(4) of the ECHR:

Everyone who is deprived of his liberty by arrest or detention shall be entitled to take proceedings by which the lawfulness of his detention shall be decided speedily by a court and his release ordered if the detention is not lawful.

At the time of writing, the UK Government, in the face of some significant opposition, intends to repeal the Human Rights Act (1998), but the international legal instruments still remain in force; critically, it remains to be determined whether the UK will voluntarily remain a signatory of the European Convention of Human Rights.

The Supreme Court judgments in the cases of *P v Cheshire West and Chester Council* and another, and *P and Q v Surrey County Council* [2014], are widely considered to be highly significant. These very significant judgments have provided clarification on the definition of a deprivation of liberty and have reduced the widespread confusion that service users, their representatives and professionals have been grappling with over the past few years. The Supreme Court found that there is a deprivation of liberty for the purposes of Article 5 of the European Convention on Human Rights in the following circumstances: the person is