

What has Human Rights got to say about Care and Dignity?

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This paper has been prepared as an introduction to some of the issues to be discussed at our forthcoming think-tank event, in Glasgow on 29th April 2009. The event will be the fourth in a series organised as part of a Knowledge Exchange project funded by the Scottish Funding Council, looking at Promoting Best practice on Equality and Human Rights in Scotland.

The aim of this knowledge exchange programme is to provide an opportunity to open dialogue on and promote an understanding of the new equality and human rights agenda with key stakeholders in the public, private and voluntary sectors across Scotland. It also aims to stimulate research on and support best practice in implementing equality and human rights policies in Scotland.

Key aims and objectives of the day

- To exchange knowledge and understanding of how the new equality and human rights agenda is impacting on the provision of care for people in long stay institutions;
- To develop a particular Scottish focus on the human rights of people in care in partnership with key Scottish institutions;
- To stimulate research on the human rights of people in care;
- To support best practice in implementing policies that promote the human rights of people living in long stay institutions in Scotland

Human Rights and Care

The concepts of equality and human rights are often, erroneously, seen as being synonymous. Human rights, however, is an overarching concept of which equality is one part. The human rights agenda combines civil and political rights as well as economic, social and cultural rights, under an overarching theory of equality and non-discrimination. The core principles of human rights include dignity and autonomy; non-discrimination; participation and inclusion; access; diversity; equality of opportunity and respect. It allows people to demand not just equal treatment, but treatment that is fair, that demands dignity, that respects freedom and that denounces harassment, discrimination or physical threat. It is the principle of human rights that prevents us from being treated equally badly.

This argument is particularly relevant to those who live in institutional accommodation including care homes, long stay hospitals or respite facilities. Much of the discussion around human rights, legislation and care for people in long stay institutions has focussed on the medical and legal assessments of capacity and procedural implications rather than on any wider implications for citizenship rights. There is a historic tension that has existed over how concepts of citizenship and rights apply to people who have conditions that may affect or are deemed to affect, their capacity to take decisions for themselves. These include people with a mental health problem, specifically dementia and learning difficulties (Boyle 2008a). A claim to citizenship is often based on a fairly paternalistic concept of the rational man (Brock 1993). Thus those considered irrational (or not male) were excluded from the rights and status of citizenship, and so excluded

from the civil right to liberty, the political right to influence governance and the social rights to be seen as equal. Thus, on a point of definition, people with mental ill health, dementia or learning difficulty have been afforded inferior status. For this reason the treatment of and provision of care for people living in long-stay institutions requires a human rights agenda more than a focus on equalities.

Care in a long term residential setting is seen as something that you turn to when all else fails. Care homes are seen as a last, and worst, resort and much emphasis in planning and developing social care is aimed at trying to keep people out of such institutions and the focus is on the rights of people to live in the community rather than the rights of people who live in such homes. As a consequence, the rights of residents of long stay institutions have been to a large extent unexplored. This study day aims to start to address these gaps.

This briefing will now examine some of the academic literature that has evaluated the HRA, focussing in particular on care and dignity. The focus mainly falls on the relevant policy pertaining to older people, people with mental ill health and anyone else in receipt of health and/or social care services. A brief outline of academic work, notably informed by Geraldine Boyle (2004; 2005; 2008a; 2008b) will follow. This work has attempted to consider the impact of the HRA on real people by considering the influence this increased focus on rights has had for older people and people who have mental ill health.

Care in Scotland

This section will outline some of the key legislation relating to care in Scotland. To begin though, it is useful to introduce the Joint Committee on Human Rights (JCHR). Following the passing of the Human Rights Act in 1998 the JCHR was established in 2001 to scrutinise every Bill to ensure that it did not clash with the HRA. In this way, the promise of the HRA should infuse each bill. Despite the intentions of the JCHR it has not fully lived up to its promise. The Klug Report (Klug 2006) has claimed that the JCHR has little power to change Bills. It has also been described as being overly legalistic, ignoring the sociological or economic impacts of legislation (Tolley 2009). Despite these claims there is some evidence to suggest that Scottish legislation relating to care, since 2001, has increasingly paid attention to rights, to dignity and to freedom of choice.

Since devolution, there have been a number of Acts designed to promote the rights of people who receive social and/or health care services, including those people who live in residential accommodation. The Adults with Incapacity (Scotland) Act 2000 (AWIA) set out the system for protecting the welfare of adults who are unable to take decisions for themselves, in Scotland. Its aim is to help adults (aged 16 plus) who lack the capacity to make decisions on some or all aspects of their lives. It enables health care professionals, carers or others to have legal powers to make financial, welfare and health care decisions on their behalf. The 2000 Act streamlined support provision for people considered to have no capacity or limited capacity to manage or choose their own provision. Crucially the Act permits individuals the right to protect the control they had over their decisions and finance by nominating a Guardian to help them make informed choices. Although the Act does not use the language of ‘assisted autonomy’ that was introduced by the Mental Capacity Act 2005 (implemented in England and Wales from 2007), it does provide a comparative framework and its aim is to optimise autonomy.

The Regulation of Care (Scotland) Act 2001 has a wider remit than the Incapacity Act 2000, and relates to all healthcare services in Scotland (including adult, child and independent services). This 2001 Regulation of Care Act launched the Scottish Care Commission. This Commission works to regulate all care providers in Scotland using the Scottish Government's National Care Standards. There are six care standards: Dignity, Privacy, Choice, Safety, Realising Potential, Equality and Diversity. Though human rights are not specifically touted as a principal aim of this legislation, it is clear from the care standards that rights are a central message of this policy. The National Care Standards are used to not only assess care providers but also to assist users of care and support services as to how to best to optimise the service they receive. For example the document '*National Care Standards: Care Homes for People with Mental Health Problems*' is one of many documents designed to help service users understand their legal rights, and to optimise their awareness of how they can exercise choice and organise support arrangements (Scottish Government 2005).

Adults experiencing mental ill health have further legislative support. The Mental Health (Care and Treatment) (Scotland) Act 2003 came into force in October 2005. It launched two new bodies: the Mental Welfare Commission and the Mental Health Tribunal. This legislation builds on earlier policy to further strengthen each person's right to autonomy and choice. Within this Act all health care users should be fully involved in all aspects of their care including assessment, treatment and support. If a person requires assistance to achieve this, then health care providers should grant this. If a case is to go to the Tribunal then any named person is eligible for non-means legal aid. This then allows all people to use the Act and Tribunal to receive useful support.

Though the legislative changes made in Scotland since devolution appear to place each person firmly at the centre of their care provision and optimise their rights to choice, there has been little work examining the impact of these policies in practice. Some work has been done exploring equivalent legislation in England and Wales.

An Evaluation of English/Welsh Policy

The equivalent English and Welsh legislation has been subjected to much greater scrutiny than their Scottish counterparts. For example Boyle (2008a) has examined the Mental Capacity Act 2005 and how it introduced the notion of 'assisted autonomy' where support is required to enable the exercise of autonomy – an idea central to any concept of citizenship for people with a mental health problem such as dementia or a learning difficulty or younger people. It argues that this is a useful way of considering the quality of care and of bringing in the Human Rights Agenda. In a study examining quality of life of older people (Boyle 2004) it was found that only half of older adults felt that they were able to make decisions for themselves, and related the lack of autonomy to mental ill health. A Scottish study by Tester et al, (2004) concluded that having control over decisions relating to autonomy and choice increased quality of life.

The 'assisted autonomy' of the Mental Capacity Act 2005 may be sufficient to increase the inclusion of some adults. The notion of assisted autonomy lies in the practice of allowing those with the impaired capacity to exploit the capacity that they do have to make rational decisions. Within this idea, the fact that the decision is assisted makes it no less autonomous recognising

that most of us make decisions with others. The issues surrounding people with dementia are particularly relevant here.

While it is acknowledged that the move to a care home may be a positive and informed choice of many individuals, sometimes the decision is made by health and social care professionals or the relatives and carers to protect the individual and, in practice excluding the individual from being involved (Moriarty and Webb 2000; Davies and Nolan 2003). The Mental Incapacity Act 2005 was designed to alleviate the tensions created by enforced institutional care. For example, Dickenson, (2001) summarized the case of a man who was admitted to a psychiatric hospital without due consideration to his wishes. His foster carers appealed on his behalf to a judicial review of the National Health Service Trust at the High Court, the UK Court of Appeal, The House of Lords (1998) and finally the European Court of Human Rights (ECHR, 2004) who found that the civil rights of the man had been compromised as his liberty had been unlawfully deprived. The 2005 Act attempted to close this loophole, thus supporting the finding of the ECHR.

While the terms of the Mental Capacity Act 2005 aim to promote a human rights message, there is concern that the practical use of the Act is limited for more people that it helps. It usefully moves the concept of capacity from a medicalised definition to a socially defined concept with tests of functionality where previously tests of cognition were used (British Association of Social Work, 2003). The Department of Constitutional Affairs (2007a) has published a Code of Practice to facilitate the work of health and social care professionals to which workers are required to 'have regard' (2007a: 2). Where an individual does not have friends or family available to consult with on decisions an Independent Mental Capacity Advocate (IMCA) should be appointed to safeguard their interests (Boyle, 2008a).

However, while the mechanisms are largely available for an individual with dementia, for example, to have 'assisted autonomy' in fact, if their decision is at odds with the views of health and social care professionals, the paternalistic view of 'best interests' carries more weight (Boyle, 2008a). Where an adult with dementia has carers or friends available to advise (even if the advice is damaging to the autonomy of the individual) they are ineligible to receive the support of an IMCA (Boyle, 2008a, Redley et al, 2006). Further despite the Code of Practice published by the Department of Constitutional Affairs (2007a) many care workers were unfamiliar with its guidance (Redley et al, 2006). The Scottish version of the Mental Capacity Act, the Adults with Incapacity (Scotland) Act 2000 has also been criticised for leaving health and social care professionals unsure about how to assess capacity (Killeen et al, 2004). Although this legislation appears to have a positive impact, it seems clear that in practice some people's rights to autonomy are not respected.

Regulation of Care

Palmer (2008) is careful to remind us that part of the problem lies not with the legislation per se, but with many care and health services being provided by the private sector (including voluntary and charitable sector): a product of thirty years of privatization and out-sourcing. While the standard of care offered by the private sector can be excellent there is some concern that it is not subject to the stringent scrutiny of public sector provision (Palmer, 2008).

The key difference is that private enterprises aim to make profit and this potentially is a priority over providing care and dignity (this is not true for many residential homes managed in the private sector, the argument though, is that it could be). In order to ensure care and dignity then, the Government must scrutinize and measure service delivery (for example via the Scottish Care Commission); Palmer (2008) however, suggests that this is not done well. Where local authorities fund services run by the private sector, the private sector should pay due regard to the legislation that impacts on the public sector, for example, the HRA, the Equality Act, the Disability Equality Act and so on. But there remains concern about the extent to which the performance of the private sector is adequately monitored. Where cases have been taken to Court under the HRA against private sector bodies providing public sector services, the Court has generally ordered that private sector bodies should not be considered bound by the HRA. Perhaps not surprisingly the JCHR were not happy with this judicial interpretation of the HRA but did not directly challenge decisions, (JCHR, 2003-4). This trend of dismissing claims made under the HRA extends to all cases heard by the House of Lords. Since October 2000 (when the HRA became enforceable) only 27% of cases have been upheld (35 of 132 cases) (Shah and Poole, 2009).

In response to the case *YL v. Birmingham City Council and others*, the House of Lords ruled in 2007 that:

‘... a privately owned care home, operating on a for-profit basis and acting pursuant to a contract with a local authority could not be deemed to be a hybrid public authority under section 6 (3)b of the HRA.’ (Palmer, 2008:593)

Thus care received in a placement funded by the private sector need not give regard to human rights under British Law, the preservation of autonomy or dignity, and can ignore the right to freedom, because they are orientated towards making profit.

Conclusion

In conclusion, there has been a proliferation of policy from both Holyrood and Westminster that has sought to protect and enhance the rights of people living in the United Kingdom. The implementation of these policies has been problematic however. As this Briefing Paper has demonstrated, the HRA has been used legalistically and rarely to regulate which Acts have been passed since 2001. Legislation relating to health and social care have gone a long way to improving the rhetoric around the support of people who rely on such services, however as many workers at the grass-roots level are still unclear about legislation, its impact must be limited. Can human rights go further to improve autonomy, choice, dignity and care in Scotland? This event seeks to explore the impact of the HRA on Scottish services and to consider how human rights can be conceptualized to the advantage of people who depend on care services.

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