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Ferrie, J. (2011) Sociology and human rights: what have they got to say about care and dignity. In: Hynes, P., Michele, L., Short, D. and Waites, M. (eds.) *Sociology and Human Rights*. Routledge: London, pp. 55-69. ISBN 9780415617970.

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Deposited on: 9 January 2017

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Sociology and human rights: what have they got to say about care and dignity?

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Abstract

The focus of this contribution mainly falls on the relevant policy concerning care in the United Kingdom pertaining to older people, people with mental ill health and anyone else in receipt of health and/or social care services. It offers an attempt to consider the impact that sociology could have on improving the ethical practices of care. Attempts to assert rights in residential care have been challenged by a dominant culture that has eroded claims to citizenship. It is argued that this is due to a legal emphasis on regulation through care standards that has limited use because it avoids the realities of care. This contribution argues that a purely legal understanding of human rights is inadequate to address the social realities of inadequate care. The treatment of and provision of care for people living in long-stay institutions requires a human rights framework that operates socially rather than legally to recognise lived experiences in order to empower and emancipate.

Keywords: care; disability movement; ethics of care; equality; human rights

Introduction

Those who receive care can be treated in ways that infringe their human rights in terms of living in discomfort, in fear, without dignity and without control. The major legislation in the United Kingdom (UK) relating to rights is the Human Rights Act (HRA, 1998)¹ introduced in 1998 which embeds the European Convention on Human Rights (ECHR) in domestic law. The HRA is reserved to Westminster meaning that it exists for the entire UK. In contrast legislation relating to health and care has been devolved to the Scottish parliament since the Scotland Act of 1998.² Therefore, the analysis presented here addresses both the Scottish response, and the distinct English and Welsh response to health and care as related to residential care. In the UK living with degrading and dehumanising treatment infringes rights afforded by the HRA: specifically Article 3, the prohibition of torture, and Article 8, the right to respect for private and family life. This contribution will examine UK policy responses to these problems and review Scottish and English/Welsh strategies for supporting receivers of care, using a sociology of human rights to unpick how such infringements can occur. Though the analysis presented is based on UK experiences, the UK is not unique in its institutionalisation – or as many would probably prefer to think of it, the move to residential care – of people who receive full time care, or with respect to the injustices experienced in these environments.

The sociology of rights is an emerging field in the UK though there have been some key and influential contributions. The works of Bryan S. Turner and Anthony Woodiwiss³ stand out as being essential in developing the social theory behind a sociology of human rights and championing further work applying sociological analysis to rights. A sociological analysis allows the exploration of the moral values and normative structures that derive from and contribute to society. Thus a sociology of human rights explores how legal and moral frameworks of rights operate and highlights where these are lacking and leading to injustice or exclusion from participation in society.⁴ Where perhaps the social theory of a sociology of human rights has become stuck, is around the notion of moral relativism. According to Turner's explanation⁵ sociology has traditionally avoided passing judgement on the processes that it examines in the name of positivist objectivity. If this truly be the case, then the scrutiny of a sociology of human rights might risk being more descriptive than useful.

However the increase in qualitative interrogations of social structures and research based on feminist and emancipatory principles over the last 30 years have changed the landscape of sociology in the UK. Relevant to this contribution is the work conducted in the field of disability studies, much of which has used feminist and emancipatory paradigms to critically evaluate the social structures that oppress and discriminate against disabled people. Emerging from a political activism, disability studies was founded on the principles

of political engagement through research. Similarly, as Turner completes his arguments (discussed in the opening contribution in this collection),⁶ it becomes clear that sociology can be used to critically evaluate the regulation of rights frameworks to pass judgement on their meaningful impact on the lives of people. This contribution considers this process with respect to how care is experienced in the UK.

This contribution aims to build upon some key theoretical ideas around care that have emerged from disability studies and from feminist literature. Both consider the role of the carer and the cared for, though it is the feminist literature that has done most to consider the rights of the carer. This focus is due to the given that the majority of paid and unpaid carers are women. This contribution confines itself to those people in receipt of care. I explain why in the course of the discussion, but the analysis is nevertheless based on a simple principle, that the needs of carers and the rights of those in care can clash, so that both cannot be realised simultaneously in some cases. For example, Article 8 of the European Convention could be used to argue that unpaid familial carers should not be required to provide 24-hour support, yet this is the position that many informal carers find themselves in. So here their right to a family life becomes threatened, but the person who is cared for may rely on this level of support to access their right to family life. Further, by considering the two together, it can seem easy to put the onus on the carer to solve the inequalities faced by the person in receipt of care, but the source of the problem does not lie with the carer. Rather the source of the problem is more ideological and therefore it is society that must transform itself in order to ensure that those who receive care are not treated in marginalised and undignified ways. These ideas have been informed from a think tank event, held in Glasgow in April 2009.⁷ The event was 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 grant was held by Nick Watson (University of Glasgow) and Sheila Riddell (University of Edinburgh). The aim of the knowledge exchange programme was 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 aimed to stimulate research on and support best practice in implementing equality and human rights policies in Scotland. I was instrumental in co-ordinating these events and participated as Discussant at the event relating to care and human rights, and some of the evidence that emerged from this event will be discussed.

The first broad section of this contribution will establish the need to give our attention to the infringements of human rights that can occur in residential care settings. The focus will then turn to the link, often made in political literature, between citizenship and rights.⁸ It will be argued that adults living in care (rather than the wider group of those living in their communities and in receipt of care) are removed from the obligations and rewards of citizenship. Further, that this marginalisation from civil participation and recognition has eroded access to rights generally and human rights specifically. In support of this argument, UK policy relating to human rights and care will be examined, and it becomes clear how the former has impacted on the latter. It is argued that people in care face barriers to their rights.

What emerges from this analysis is that the HRA is not being used as a tool to inform the regulation of care practices. One of the problems identified is that the HRA does not have to be considered by residential care providers working wholly in the private sector. This loophole has been addressed partially in English and Welsh policy. The final section will return to the notion of citizenship and question why a relatively rich and relatively democratic state such as the UK can recognise the need for protection of rights at the legislative level, but fail to manage a system whereby these rights are assumed for those living in care. The question of autonomy seems central to this debate in that rights continue to be afforded to those who are able to challenge the absence or infringement, but not to those who are unable. The conclusion considers to what extent the sociological study of human rights can and should be used to challenge this status quo, and to consider how all can be free to expect a threshold of rights irrespective of their conformity to the notion of citizen.

Human rights and care

As stated, this contribution will focus on adults who live in institutional accommodation including care homes, long-stay hospitals or respite facilities. At the think tank event, Gillian Dalley of the Relatives and Residents Association⁹ reported dehumanising and degrading treatment in long-stay institutions: her focus was mostly on residential care homes. Such examples included: the implicit and explicit discouragement of complaints; neglect (pressure sores, untreated heart infections, residents left in their own faeces); the removal and destruction of personal property; dehydration and sexual assault. The British Institute for Human Rights¹⁰ have also catalogued a plethora of insults against older adults living in residential homes including residents being given meals while on commodes, and left naked in rooms with the door onto a public corridor open. Also presenting at the think tank event, the Scottish Human Rights Commission, the Office for the Scottish Commissioner for Children and Young People and the Scottish Association for Mental Health¹¹ revealed that older people, people with mental health problems, young people and disabled people can be vulnerable to this breakdown in the ethics of care. Within these examples people are dehumanised because they are seen as inferior, vulnerable or defenceless. What seems clear is that the majority of people would consider such treatment against themselves to be an infringement of their human rights, yet little is done to harness this sense of what is right and what is wrong, to challenge the care received by a minority (and to be clear, this is a minority of the people who receive care, many do not have their rights infringed).

Much of the academic literature 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. This is a danger when a problem is understood in legalistic rather than sociological terms, this is an argument that I will return to. There is an historic debate over how concepts of citizenship and rights apply to people who have conditions that may affect, or are deemed to affect, their capacity to make decisions for themselves. These include people with a mental health problem, dementia and/or learning difficulties.¹² Rawlsian¹³ concepts of social contract theory for example emerged from liberal political theory and argued that an individual must have the capacity to contribute both in terms of production and politically in order to fully be considered as a citizen, and afforded the rights of citizenship. The American philosopher Martha Nussbaum¹⁴ has used her development of the capabilities approach¹⁵ to criticise social contract theory (assuming within this critical approach that social contract theory describes actual social structures) for awarding status only to those who are actively contributing, thus marginalising those who may once have contributed but are no longer¹⁶ (older people), those who have not yet been permitted to contribute (younger people) and those who have faced barriers to being able to contribute (disabled people).¹⁷ While a contractual society might work well for the majority it fails to face the social barriers it creates for many. A claim to citizenship is often based on a fairly paternalistic concept of the rational man.¹⁸ 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. This has consequences for those who receive care. According to Reynolds and Walmsley¹⁹ the situation is compounded because as well as not being recognised as active citizens, people who receive care are reduced to a state of dependency. This is because the discourse around care has largely focused on children, and particularly babies. As a result, it tends to be assumed that anyone in receipt of care has the same level of frailty, vulnerability and lack of autonomy as young children. Because many people who access residential care have mental health problems, dementia, a learning disability or other form of impairment, they are, on this point of definition afforded inferior status by society, and face barriers to active citizenship. A clear argument against this oppression could have come from the disability movement; however as Shakespeare²⁰ notes, care became synonymous with oppression (rather than being seen as a tool for the oppression that came from dominant social ideologies) and was rejected from being a legitimate concern of the movement.²¹

If care was considered by the disability movement, it was in the guise of autonomous independent living.²² The aim was to fight for service providers and ultimately the state to deliver sufficient care so that disabled people had the same freedoms as non-disabled

people. Where this has been achieved, the rights of the person in receipt of care have a fairly good chance of being met. It is an empowering and emancipating solution but requires a particular set of circumstances to work. Direct payments have been developed to allow people in receipt of social care to manage this care, being given a budget to spend rather than direct access to care services.²³ Not everyone can or wants to manage this. Many people who receive the level of care that has led them to choose (or have chosen for them) residential care are ineligible for direct payments or are unable to exercise autonomy or independence. But more than this, there is less control, less independence and less autonomy than there needs to be, and it is this erosion of recognising the individual as having the capacity to be an active citizen (and holder of the right to control over their own decisions) that needs attention. Only through this focus, will it be realised that such individuals have human rights, and that these are currently infringed.

An emphasis on care in the community in the UK has formed a culture whereby care provided in long-term residential settings are seen as something that one turns 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. The right to live in the community intersects strongly with the HRA, and the right to a family life.²⁴ As a consequence, the rights of residents of long-stay institutions have been to a large extent unexplored.²⁵ This contribution addresses these gaps.

The impact of the Human Rights Act (1998) on care

Though the HRA exists and can be used to fight cases, the legal process can take a great deal of time. A review of Scottish case law revealed that no case has challenged an infringement of rights experienced by someone living in residential care.²⁶ As stated earlier Articles 3 and 8 of the European Convention are the most relevant. Article 3's prohibition of torture protects physical integrity and abolishes degrading and inhuman treatment. Where this has been considered in the European Court of Human Rights (ECtHR), it has been concluded that such treatment would need to be commensurate with a criminal act (for example, actual bodily harm) to be considered. Article 8 affords the right to respect for private and family life. A combination of the two could be used to ensure the positive obligation placed on public authorities to ensure respect for physical and psychological dignity of individuals is not infringed.²⁷

Dalley's²⁸ presentation at the think tank event represented members of the Relatives and Residents Association and this organisation collected data concluding that in reality, older people living in residential care do not want to complain, many more do not feel empowered to use a legal route to redress, and the few people who do feel able to challenge degrading treatment in residential care homes often die before their legal challenge runs its course.²⁹ As a result, the HRA has rarely been used in practice. Personal claims under the Act force people into a legal process where a knowledge of the legislation or possessing funds to hire a solicitor or lawyer with such knowledge is a pre-requisite for action. Personal claims are not the only route the HRA has to impact on care; it is useful to consider the work of the Joint Committee on Human Rights (JCHR). Following the passing of the HRA in 1998 the JCHR was established by the UK parliament in 2001 to scrutinise every bill to ensure that it did not clash with the HRA. In this way, the promise of the HRA had potential to infuse each bill. Yet despite the intentions of the JCHR it has not fully lived up to its promise. The Klug report³⁰ reviewed the performance of the JCHR and examined the early challenges it made to bills working their way through the legislative process and found that recommendations made by the JCHR were not always implemented. In fact the Klug report claimed that the JCHR has little power to change bills at all. It has also been described as being overly legalistic due in part to the interpretation of the committee's role to be to give "quasi-judicial" legal advice,³¹ in terms of focusing on the extent to which the concise terms in a bill intersect with the concise terms of the HRA. The JCHR are less concerned with considering the likely consequences of how a bill might be interpreted once it has become legislation and how it will impact on real people, and then considering how this intersects with the Human Rights Act. In considering these legal intersections, and due in part to the over-representation of legal professionals (compared with the population of parliament) the JCHR neglects the social and economic impact of legislation.³² Despite these claims there is some evidence to suggest that UK legislation relating to care, since

2001, has increasingly paid attention to rights, to dignity and to freedom of choice. The next section will outline some of the key and most recent legislation relating to care in Scotland.

Care policy in Scotland

It is clear that those who create policy in Scotland have recognised that people who receive care require more support to protect their rights than those who do not. If this position was not held, then legislation would not need to place this duty of support on health and social care providers. However terms such as 'rights' and 'human rights' do not feature explicitly in the legislation. The aim of this section is to show how 'autonomy' and 'control' have become important keywords infusing recent legislation around care. The concepts of autonomy and control have been recognised as necessary capacities in order to function as active citizens, but the pursuit of autonomy has replaced a pursuit of rights. Legislation has then opted to focus on finding ways to 'correct' or 'optimise' the individual in order to allow them to 'fit in' with society, rather than examining how society can change to accept the differences in people's ability to participate.

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)³³ set out the system for protecting the welfare of adults who are unable to take decisions for themselves, in Scotland. This is particularly relevant to Article 8 of the HRA and decisions around achieving a private and family life. 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. Thus those working closely with eligible adults can assist them to take control over key elements of their lives. The Act has been criticised though for leaving health and social care professionals unsure about how to assess capacity.³⁴ AWIA streamlined support provision for people considered to have no capacity or limited capacity to manage or choose their own provision. Crucially the Act permitted 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 rights or of 'assisted autonomy' that was introduced by the Mental Capacity Act 2005 (implemented in England and Wales from 2007 and discussed in the next section), it does provide a comparative framework and its aim is to optimise autonomy. The Regulation of Care (Scotland) Act 2001³⁵ has a wider remit than the Incapacity Act 2000, and relates to all healthcare services in Scotland (including adult, child and independent services). This Regulation of Care (Scotland) 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 as it uses concepts through which rights are usually delivered, (for example 'dignity' and 'choice'). 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. In this way the standards aim to trigger change through surveillance and also permit empowered people to utilise them on a more individual basis. 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.³⁶ Adults experiencing mental ill health have further legislative support. The Mental Health (Care and Treatment) (Scotland) Act 2003³⁷ came into force in October 2005. It launched two new bodies: the MentalWelfare Commission and the Mental Health Tribunal. This legislation builds on earlier policies, seeking to further strengthen each person's autonomy and choice. Again, the legislation was required because it was understood that people with mental health problems had their rights infringed in terms of being marginalised from active participation in making choices. 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 nonmeans-tested legal aid. This then allows all people to use the Act and Tribunal to seek useful support. People with a challenge to make must still make a legal challenge, but the Act should remove the pre-requisite of having personal funds to support their challenge. The Act though does not recognise the lack of empowerment or the enforced vulnerability felt by many people with mental health problems who have received care, and therefore avoids a sociological view of the issue.

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 choices, there has been little work examining the impact of these policies in practice. Some work has been done exploring legislation relating to the same care issues in England and Wales to which the focus now turns.

Care policy in England and Wales

The equivalent English and Welsh legislation has been subjected to much greater scrutiny than in Scotland. For example Boyle³⁸ has examined the Mental Capacity Act 2005³⁹ 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 for younger people. Boyle 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 the quality of life of older people⁴⁰ it was found that only half of older adults felt that they were able to make decisions for themselves. Further the study related this lack of autonomy to the development of mental health problems (rather than the opposite situation of mental health problems leading to a restriction of autonomous behaviour). A Scottish study⁴¹ concluded that having control over decisions relating to autonomy and choice increased quality of life. These studies clearly show how essential control and autonomy are to having a sense of well-being. They also show how depleted a person's sense of empowerment can become as their autonomy shrinks and mental health problems increase. Any legislative strategy that relies on the individual to make a legal challenge ignores the social reality of individuals in receipt of care, who can easily lose their capacity to challenge.

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 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. This argument is a convincing one. As social beings people do generally seek the advice of others when making many decisions, those that impact in limited ways and those that impact more profoundly on us. Therefore the idea that autonomy needs to be proven before individuals are afforded the right to make decisions for themselves becomes an ideal to which citizens do not normally need to conform. Most people do not need to prove their capacity to be autonomous, so it is peculiar that we force certain people over this hurdle, or restrict their rights should they fail to comply. Further, it is a given freedom that we are able to make decisions that are emotional rather than rational, as adults we are generally allowed to make our own mistakes. Quite who determines what a 'rational' decision is, is not adequately covered by this legislation.

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 relatives and carers to protect an individual, and in practice the individual involved is excluded from the decision being made.⁴² The Mental Incapacity Act 2005 was designed to alleviate the tensions created by enforced institutional care. For example, Dickenson⁴³ summarised the case *R. v. Bournemouth Community and Mental Health NHS Trust (1998)*⁴⁴ 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 Lords⁴⁵

and finally the European Court of Human Rights.⁴⁶ Though the House of Lords decided that the common law of necessity could justify detention; the ECtHR viewed such detention as a violation of human and civil rights. The Mental Health Act of 2007⁴⁷ attempted to close this loophole, thus supporting the finding of the ECtHR. What this example exposes is the difficulties in using a legal route: a lengthy and involved process to deliver rights that in practice often require to be acknowledged quickly.

The Mental Capacity Act 2005 has paid due consideration to the HRA, for example Article 4(5) promotes the right to life consistent with Article 2 of the European Convention and Article 6(5) shows that forceful restraint of adults under the Mental Capacity Act could contravene Article 5(1) of the Convention. What is less clear is whether this legal protection translates into a practical and useful tool. Much of the Mental Capacity Act is framed to allow the detention and treatment of adults on the grounds that they lack capacity. It does though require a stringent focus on what capacity is and how it is limited with each individual. The Act 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.⁴⁸ The Department of Constitutional Affairs has published a Code of Practice to facilitate the work of health and social care professionals to which workers are required to 'have regard'.⁴⁹ 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.⁵⁰

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.⁵¹ 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.⁵² In this situation, a person whose views are at odds with carers or friends has no route to autonomy because they cannot utilise the IMCA. Yet it seems that many of the people in this situation are the most in need of this independent support.

A further issue has dampened the impact of this legislation. Despite the Code of Practice published by the Department of Constitutional Affairs⁵³ many care workers were unfamiliar with its guidance.⁵⁴ Of course this is hardly surprising. Sociological approaches to policy implementation have shown that full knowledge of the law is beyond the capacity (in terms of working hours available to them) for front line workers. Lipsky's⁵⁵ hugely influential and eloquent concept of 'street level bureaucrats' showed too how policy implementation tends to be subjected to interpretation as it is assimilated into existing working practices. It is not surprising that those working in health and care do not possess knowledge of the law. The Mental Capacity Act (2005) is written so that this knowledge is assumed in order to deliver protection: without its knowledge, the Mental Capacity Act cannot be appropriately implemented. Although this legislation appears to have a positive impact, it seems clear that in practice some people's rights and autonomy are not respected.

Regulation of care in the United Kingdom

Palmer⁵⁶ is careful to stress 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 privatisation 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.⁵⁷

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 can be). In order to ensure care and dignity then, the government must scrutinise and measure service delivery (for example via the Scottish Care Commission); Palmer⁵⁸ 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, HRA, the Equality Act 2006 which synthesised existing anti-discrimination legislation including that related to age,⁵⁹ 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 a UK 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.⁶⁰ 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 per cent of cases have been upheld (35 of 132 cases).⁶¹

In response to the case *YL v. Birmingham City Council and others*,⁶² 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.⁶³

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. The Health and Social Care Act of 2008⁶⁴ does go some way to address this issue, and operates in Scotland and England and Wales to ensure that care funded by the state (whether it be in state-owned or privately-owned care homes) is protected by the HRA.⁶⁵ The important point to draw from this is that many people who live in residential homes may assume that they do not have rights, or the protection of the law, because some people do not. Thus a culture pervades of being unable to challenge degrading treatment, and of having limited autonomy, even though some people receiving state-funded care are able to legally challenge this.

In pursuit of autonomy

Notions of autonomy pervade legislation around care but at the cost of a full discourse on rights. The advances in legislation to help protect the quality of care given to those in our society that are dependent upon it, is perhaps proof that culturally and socially the UK is organised and run in a way that excludes care, benevolence and those in receipt of care until the needs of the majority have been met. This is perhaps aligned to Nussbaum's⁶⁶ argument that the design of public spaces continues to exclude disabled people, thus promoting the idea that disabled people are not the public, they are not to be counted or considered as relevant.

Thus, and as noted earlier, on a point of definition, people who receive care are given an inferior status. Further, equality has not been built into UK systems as those in receipt of care are not presented culturally, socially, or politically as equals. So re-balancing this power requires a different response than more legislation. More legislation would entrench the assumption that legal redress is the only route to the acquisition of rights. It has been argued in this contribution that this route is not accessible for many. A greater focus on a sociology of human rights can be used to highlight the inadequacies of this UK legal system, and create pressure to use human rights to create a threshold of care where inhuman and degrading treatment cannot occur. In the current system, rights need be infringed before someone is entitled to make a costly, lengthy, laborious and intimidating legal challenge. A new implementation of the HRA could ensure that the ethics of care transcend the realities of financial cut-backs, uneducated carers and undignified treatment. This could be monitored through current regulatory frameworks such as the UK-wide Equality and Human Rights Commission, or the Scottish Mental Health Commission, rather than relying on individuals making legal challenges.

What is needed is an ethical examination of the tension between autonomy and dependency. The two concepts seem placed dichotomously with autonomous decisions only managed through advocacy. Such manipulation is unnecessary: all people are at once autonomous and dependant. As a society we should try to apply this fluidity in order to recognise people who are cared for as being active citizens. The dichotomous approach carries weight in practice: if a person needs care, and particularly if the state is asked to pay for it, then that person cannot be autonomous. And it is this fatalistic message that has essentially eroded the application of the HRA and prevented its impact on care.

Shakespeare⁶⁷ clarified this argument when critiquing the disability movement's fight to end dependent care structures. These are socially created structures that have marginalised the support of disabled people outside of the mainstream (for example, special education).⁶⁸ The medical model is used to describe a reality where disabled people were marginalised from making their own decisions. Rather medical and social care professionals were considered to have the expertise and subsequent power to place disabled people in institutions.⁶⁹ The disability movement challenged this approach and fought for the empowerment of all disabled people. Oliver, Finkelstein and others⁷⁰ campaigned politically and through academic literature for a move towards independent living.⁷¹ Within this literature, autonomous living was seen as attainable if only social structures permitted it. For example, direct payments (a system whereby eligible adults had control over their own social care budgets so that they could choose and manage their care support) were used as a system of emancipating disabled people from institutional care.⁷² For some, this transition from dependent to autonomous living is vital, but for many care and dependency is vital and necessary. For example, it has been argued⁷³ that independent living will not suit the needs of most people with intellectual disabilities.

But Shakespeare⁷⁴ begins an argument that needs further focus. He says that neither autonomy nor independence are requirements for care that optimises rights, respect and dignity. Therefore this over-scrutiny of the wits of those in receipt of care allows us to bypass the duty of care that befalls society. I would agree. To impose a situation where adults in care must be rational and autonomous in order to be given the rights of citizenship (and subsequently the right not to be degraded or dehumanised) is to require something more of them than most of us need to live up to. This happens because the legislation necessarily uses a legal framework, where people are categorised as being in need of help (inferior status). A sociological understanding is needed to move away from legalities and consider morals and inform the public policy debates.

Tronto⁷⁵ has argued that the principles of rights have remained as regulations and rules, beautiful concepts that have failed to impact on the ethics of care. Human rights should influence care in a practical sense, but must first escape from its legal basis, and be applied meaningfully perhaps via a collective awakening to social responsibility.⁷⁶ This process is a social one. We must not be caught in dominant understandings of citizenship that emphasise notions of autonomous individualism.⁷⁷ The absence of reciprocity in a care relationship only matters when examining the individual, but a sociology of human rights allows us to look at our collective attitudes, and to our moral responsibility to ensure that care does not fall below the standards imposed by the HRA.

Conclusion

In conclusion, there has been a proliferation of policy from both the Scottish parliament at Holyrood, and the UK's parliament in Westminster that has sought to protect and enhance the rights of people living in the UK. The implementation of these policies has been problematic however. As has been demonstrated, the HRA has helped maintain a legalistic approach to rights in the UK and rarely to regulate the Acts that have been passed since 2001. However this legalistic focus has failed to examine the extent to which new legislation may infringe the rights of people in practical terms because it fails to examine their social and economic impact. Legislation relating to health and social care has gone a long way to improving the rhetoric around the support of people who rely on such services, however as many workers at the grassroots level are still unclear about legislation, its impact must be limited. Part of the reason for this may be the number of policies that now exist to support a minority of the population. It is unfeasible that some of the lowest earning workers in the UK (that is, care workers) should in their spare time (for they are often paid to care by the hour) become familiar with the Human Rights Act, the Equality Act and the Mental Incapacity Act and so on.

Can human rights be extended in scope to improve autonomy, choice and dignity for people in receipt of care? It is a pressing problem for society in the UK. As social research and every news item on ageing informs us, it is a problem that is getting worse as the UK will soon have more people post-retirement age than in any other time in history. But the

problems usually get framed in terms of 'costs'. Rather, sociology should have something to say about the experience of care and the impact that the relegation of people into a substatus category has on us all. Allowing the most marginalised in our society to live with rights empowers us all to recognise that we live with rights. Ensuring that people whose rights are infringed can and do challenge their environments will lead to an expectation by all that some degrees of degradation are unacceptable. Rights are the route to ending the dehumanising, undignified and un-autonomous lives lived by many people in receipt of care. Once this is ended, the stigma of care will no longer have its impact. Perhaps even the disability movement will be able to accept the reality that many people live with the reality of care: care will no longer be a dirty word.

Acknowledgements

This contribution has been informed from a think tank event, held in Glasgow in April 2009. The event was 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 grant was held by Nick Watson (University of Glasgow) and Sheila Riddell (University of Edinburgh). I worked full time as a research fellow on this project.

This contribution has been developed from a paper presented to the British Sociological Association's Sociology of Rights Study Group at a Human Rights Workshop held on 30th October 2009 at the Institute of Commonwealth Studies in London.

Notes

1. Human Rights Act, 1998 abbreviated here to HRA, http://www.opsi.gov.uk/acts/acts1998/ukpga_19980042_en_1 (accessed 18 February 2010).
2. The Scotland Act 1998 (Transfer of Functions to the Scottish Ministers, etc.) (No.2) Order 1999 created a Scottish parliament and devolved governance over many sectors including health, social care and education. Some legislation reserved to Westminster (including the HRA) takes precedence over devolved legislation so that how the HRA has impacted in Scotland can be considered in comparison with England and Wales, http://www.oqps.gov.uk/legislation/uk/si/si1999/uksi_19993321_en_1 (accessed 18 February 2010).
3. Key contributions to date include A. Woodiwiss, *Human Rights* (London: Routledge, 2005); R. Morgan and B.S. Turner's edited book *Interpreting Human Rights: Social Science Perspectives* (London: Routledge, 2009); and L. Morris's edited book *Rights: Sociological Perspectives* (London: Routledge, 2006) that championed the work conducted at the University of Essex.
4. L. Morris, 'Sociology and Rights – An Emergent Field', in *Rights: Sociological Perspectives*, ed. L. Morris (London: Routledge, 2006), 1–16.
5. B.S. Turner, 'A Sociology of Citizenship and Human Rights: Does Social Theory Still Exist?', in *Interpreting Human Rights: Social Science Perspectives*, ed. R. Morgan and B.S. Turner (London: Routledge, 2009), 177–199.
6. P. Hynes, M. Lamb, D. Short and M. Waites, 'Sociology and Human Rights: Confrontations, Evasions and New Engagements', *The International Journal of Human Rights*, 14, no. 6 (2010): 811–832.
7. N. Watson, J. Ferrie, S. Riddell, S. Edward and E. Weedon, 'What Does the Human Rights Agenda Have to Say about Care and Dignity?', CREID Briefing No. 20, 2009, http://www.creid.ed.ac.uk/Papers/briefing20_may09.pdf (accessed February, 2010). The Human Rights and Care event was the fourth in a series of five-day events. The aim was to bring together academics, public and voluntary sector workers, equality groups and those they represent and relevant non-government organisations working in Scotland to exchange knowledge. Delegates were invited to reflect on the impact of equality and human rights frameworks on: further education; asylum and migration and the equality strands. Further information about the other events in this Knowledge Exchange series can be found at: <http://www.creid.ed.ac.uk/papers> (accessed 19 February 2010).
8. B.S. Turner, 'A Sociology of Citizenship and Human Rights' 177–199.
9. G. Dalley (2009), in Watson et al., 'What Does the Human Rights Agenda Have to Say about Care and Dignity?', 1. Dalley presented a keynote address at the 'Human Rights and Care' think tank event in her capacity as Chief Executive of the Relatives and Residents Association, an organisation that campaigns for access to adequate care. Dalley has written about the care needs of disabled people and older adults. For example: G. Dalley, *Disability and Social Policy* (London: Policy Studies Institute, 1991); and G. Dalley, *Ideologies of Caring: Rethinking Community and Collectivism* (London: The Macmillan Press, 1988). This reference relates specifically to the presentation given at the think tank event and a synopsis of this is provided in Watson et al., 'What Does the Human Rights Agenda Have to Say about Care and Dignity?'
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11. Watson et al., 'What does the Human Rights Agenda Have to Say About Care and Dignity?'
12. G. Boyle, 'The Mental Capacity Act 2005: Promoting the Citizenship of People', *Health and Social Care in the Community* 16, no. 5 (2008): 529–37.
13. Rawls wrote about the social contract theory throughout his career, but notable references include: J. Rawls, *A Theory of Justice* (Cambridge, MA: Harvard University Press, 1971); and J. Rawls, 'Kantian Constructivism in Moral Theory' (Dewey Lectures), *Journal of Philosophy* 77 (1980): 515–71.
14. M. Nussbaum, *Frontiers of Justice; Disability, Nationality, Species Membership* (The Tanner Lectures on Human Values) (Cambridge, MA and London: The Belknap Press, 2006).
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17. M.C. Nussbaum, *Hiding from Humanity: Disgust, Shame and the Law* (Princeton, NJ: Princeton University Press, 2004), 176–7.
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22. A. Brechin, 'What Makes for Good Care?', in *Care Matters: Concepts, Practice and Research in Health and Social Care*, ed. A. Brechin, J. Walmsley, J. Kalz and S. Peace (London: Sage, 1998), 170–188.
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62. *YL v. Birmingham City Council*, [2007] UKHL 27, [2008] 1 AC 95.

63. *Ibid.*, 54; Palmer, 'Public Functions and Private Services', 593.

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65. *Ibid.*, 62; Health and Social Care Act 2008, Section 145 (1–5).

66. M. Nussbaum, *Frontiers of Justice: Disability, Nationality, Species Membership* (The Tanner Lectures on Human Values) (Cambridge, MA: The Belknap Press, 2006); M. Nussbaum, *Hiding from Humanity: Disgust, Shame and the Law* (Princeton, NJ: Princeton University Press, 2004), 176–177; D. W. Brock, *Life and Death: Philosophical Essays in Bio-medical Ethics* (Cambridge: Cambridge University Press, 1993).

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70. Early scholars contributing to the recognised discipline of the disability movement graduated from activism into academia. Political activists such as Vic Finkelstein and Mike Oliver had campaigned for equality in groups such as UPIAS (Union of the Physically Impaired Against Segregation, *Disability Challenge*, vol. 1 (London: UPIAS, 1981)) and the British Council of Disabled People, producing the 'Social Model'. The model was a conceptual tool to distinguish between impairment and the social, physical and structural barriers that produce disability.

Jenny Morris provides an engaging and concise introduction: Morris, 'Impairment and Disability', 1–16.

71. M. Oliver, *Disability, Citizenship and Empowerment* (Milton Keynes: Open University Press, 1993).

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