JRF scoping paper:
Rights, responsibilities, risk and regulation

Risky business?

Stuart Marchant

September 2011

This paper:

- sets important issues relating to positive risk-taking in adult social care in a legal context;
- considers how current care provision impacts on the human rights of service users; and
- analyses the extent to which the present regulatory and commissioning frameworks stifle or encourage risk-taking in adult social care.

The Joseph Rowntree Foundation (JRF) commissioned this paper primarily to inform our own thinking, as we scope a potential new programme on Rights, responsibilities, risk and regulation. How do these four themes connect in the lives of adults who use care and support? How do rights and responsibilities feature when it comes to weighing up risk in the lives of people involved in caring relationships? What needs to change, for example in the protective shell of regulation, to enable people to have good lives?

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Executive summary

This paper is a review of the scope for risk-taking within current adult social care policy, legislative and regulatory frameworks: what is the impact of these arrangements on the rights of the individual?

Adult social care provision is a fast-changing service that combines the interests and responsibilities of a whole range of stakeholders including individuals, their families, state organisations, regulators and care providers in the public, private and voluntary sectors.

At a time when policy and best practice favours the greater personalisation and individualisation of care, it is opportune to assess how and to what extent services are developing in a way which protects and promotes the rights of individuals to live their lives to the fullest. A realistic assessment of this must have regard to the framework within which social care services are delivered.

Human rights legislation requires that the state and its agencies (which now includes many – although not all – providers of private and voluntary sector care homes following the enactment of the Health and Social Care Act 2008) protect the rights of individuals to live autonomously and with dignity. The courts have upheld the right of people to enjoy personal decision-making about all aspects of their life and care and have promoted the importance of living socially within community. Both aspects of this will inevitably mean that providers of care must accept and facilitate risk-taking, but it also means that commissioners and regulators should allow and encourage them to do so.

Public sector commissioners and care providers each have their own distinct responsibilities towards people who need and use care services and we can often see a tension between how those responsibilities are interpreted against a policy direction of allowing and encouraging people to take risks as part of their everyday lives.

The social care sector is heavily regulated, principally by the Care Quality Commission but also through quasi-regulation via contract monitoring by purchasers of care, namely local authorities and primary care trusts (PCTs). Effective regulation must have a rights-based approach but the balance between promoting autonomy and its inherent risk on the one hand, and protecting the vulnerable from sub-standard care practices on the other, can be difficult to strike.

Thus we see that there are numerous obstacles to social care users leading fully autonomous lives, and also to the extent to which providers or others feel capable of encouraging them to do so. Strategies are emerging that begin to break down the risk-averse culture which impacts on the ways in which rights-based care can be allowed to flourish, but we still have some way to go. To best maximise the long-term outcomes, it is suggested that at least a medium-term approach to developing care practices be adopted across the sector by those responsible for commissioning, delivering and regulating services, and that encouragement rather than fear of penalty is the best way to achieve these aims.

Scope of this paper

In the foreword to the November 2010 Department of Health guidance document on managing risk for people with dementia, *Nothing Ventured Nothing Gained: Risk Guidance for People with Dementia* (Department of Health, 2010a), the National Clinical Director for Dementia sums up the issue at the heart of this paper:

> *We all face risk in our everyday lives and regularly make judgements, sometimes unconsciously, about risks and benefits for everyday actions. It is a challenge to tread the line between being overprotective (in an attempt to eliminate risk altogether) while respecting individual freedoms. The trick is giving people the opportunity to live life to the full, while at the same time making sure they are properly safeguarded*. (Burns, 2010)

The purpose of this paper is to stimulate thought about the interface between autonomy, individualisation, protection and control in the way that adult social care is delivered and monitored. This is, more in practice than in theory, a complex dynamic which reflects the tension between social policy and regulation, especially where regulation is perceived as punitive rather than facilitative.

Wherever there is reliance upon others, the freedom of individuals to live their lives to the fullest is curtailed by different barriers to autonomy which manifest themselves in the experiences of service users. These experiences reflect the attitudes of providers, commissioners and regulators towards the taking of risk by service users to who they owe a duty of responsibility, and are in turn affected by policy drivers which influence what these stakeholders see as the scope of their role within the system. Consequently, risk is embraced and encouraged to differing degrees.

People will have different views about the responsibility that providers have to those in their care. Ideally, individuals could choose what, for them, is an acceptable risk, so this is not a problem – a society diverse in its attitudes is a rich one. However, where individuals lack capacity it is for others to judge what is in their best interests and here the situation is more difficult.

This is particularly true as it would appear that the responsibility to protect and promote human rights applies to differing degrees depending on whether a person is being cared for in the public or private sector, and also whether he or she is funded through health or social care or is publicly or privately funded.

The opposite of risk is control, the former being the description of a chance event and the latter being the attempt to prevent anything unwanted from happening. Wherever there is a control element, this will have a direct impact on people (whether or not they are cognisant of it) who rely upon care services. This is understandable and it is a logical expression of society's paternalism towards those who are seen as vulnerable; but is it compatible with the rights that individuals have to live their lives with as much freedom as is possible, as reflected in Article 8 of the European Convention on Human Rights?

Some people are risk positive and others are risk averse, in a whole range of different contexts. It is commonly said that those who deliberately take risks for themselves never feel more alive than when they are doing so. But is the concept of risk-taking a crucial element of care or is it, rather, the antithesis of care? Can we or must we impose on carers the requirement to allow risk-taking by those who are in their care? Is a crucial part of care actually not caring? Or, better put, is it important that we allow reasonable risks whilst accepting that there will sometimes – by definition, given that there is no perfect way to manage the risks concerned – be adverse consequences for individuals? Are carers entitled to, obliged to, or prohibited from, allowing vulnerable people to put themselves at risk in the name of a quality of life that has a personal value to them even if it makes things more difficult for others? Where does the balance lie? Is the optimum position realistically achievable, and can it be facilitated through our system of safeguarding and regulation against a backdrop of funding restrictions?

(By way of anecdote, I was once asked about the risks involved in endorsing a specialist service that provided group accommodation for people who were described as having active suicidal thoughts while being simultaneously resistant to traditional psychological therapies. Here, the potential therapeutic benefit that could be derived through mutual support and self-help should be weighed against the risk that the group may encourage suicidal tendencies among its members. Despite their belief in the project, and although they had a range of professionals – including GPs, psychiatrists and lawyers – supporting them, the proprietors knew that their approach was untried, and that there could be pitfalls ahead. They are quoted as saying ‘The worst thing… will be the first death on the premises. Realistically … it is bound to happen sooner or later’. Will that death reflect the failure of the service or the crystalisation of an inherent but acceptable risk?)

In this paper, I concentrate on risk in the context of risk-taking by people who use social care services. I will touch on, but not analyse in detail, other issues such as reputational and organisational risks, and the threat of litigation, that providers, commissioners, and regulators face and which impact on their corporate behaviours.

I note that, through necessity, I have had to generalise my comments about the approach of the numerous agencies involved in care, be they commissioners within local authorities, social services departments or regulators. I do not doubt that there are very positive practices and, on behalf of the Joseph Rowntree Foundation (JRF), I encourage people to provide details of progressive examples.

It should be noted that the sections on the policy and regulatory context in this paper focus primarily on arrangements in England although these generally reflect the situation elsewhere in the UK. The application of basic human rights principles relates, of course, throughout Europe, although specific references to legislative inclusion of human rights protections through the Health and Social Care Act 2008 relate only to England. The concepts and opinion aspects within the paper have universal application and ought to reflect the need to accept culturally different approaches to care practices as necessary in a multicultural society.

Background to adult social care

The term ‘social care’ covers a wide range of services that can help people to carry on their daily lives. The range of assistance spans residential care (including nursing care), supported living arrangements and domiciliary care, where carers attend people’s homes to assist in daily living tasks and to provide care and nursing.

In 2007/8, 1.77 million people in England were supported through the provision of adult social care (NHS Information Centre, 2009). The government has predicted that a further 1.7 million people will need to access adult social care within the next 20 years (Care Quality Commission, 2010).

Who are the people accessing care? Put plainly the group consists of both older and younger people: those with learning disabilities, mental health problems (including age-related dementia), and physical health problems or impairments (including the frail elderly and those who have severe injuries). The make-up of this group consists of those who have mental capacity to make their own decisions about their care, and those who don’t.

The majority of social care is provided by private organisations and individuals with a small amount of provision coming from local authorities and the health sector. However, the majority of funding for adult social care comes from the state and is managed through state contracts.

Adult social care is one of the biggest issues in the political arena today. The Coalition Government is tasked with overseeing the provision of care for an ageing population at a time when resources and funding are severely restricted. It has already set out its initial thoughts for the greater integration of health and social care in a White Paper (Department of Health, 2010b), published last November, and a programme of reform is underway which will be heavily influenced by the Law Commission’s project on the reform of Adult Social Care (The Law Commission, 2011).

The Coalition Government also published its public health White Paper, *Healthy Lives, Healthy People: Our Strategy for Public Health in England* in November 2010 (HM Government, 2010) with a Bill expected in early 2012. This White Paper places emphasis on the values of freedom (to choose the services which are right for the individual), fairness (how does society pay for care), and responsibility. On responsibility the government states:

> *Social care is not solely the responsibility of the state. Communities and wider civil society must be set free to run innovative local schemes and build local networks of support. There are already some hugely successful examples of how this approach can help reduce people’s dependency on care services, such as the Southwark Circle initiative in London, Timebank schemes and complementary currency schemes that allow people living far from their relatives to partner with local people in the same position to provide reciprocal care.*

> *Care must again be about reinforcing personal and community resilience, reciprocity and responsibility, to prevent and postpone dependency and promote greater independence and choice.*

The government's vision for a modern system of social care is built on seven principles, one of which is 'protection: there are sensible safeguards against the risk of abuse or neglect. Risk is no longer an excuse to limit people's freedom' (Department of Health, 2010c). This is an important recognition of the negative impact that paternalistic risk management can have on the basic rights of service users to live freely and an indicator that commissioners and regulators need to promote a shift away from restrictive risk management practices.

The law related to adult social care is overly complex. In 2008, the Law Commission referred to it as 'inadequate, often incomprehensible and outdated' (The Law Commission, 2008) and has recommended that the 'confusing patchwork of conflicting statutes enacted over a period of 60 years' be simplified and, wherever possible, condensed into a single piece of modern legislation (The Law Commission, 2011).

The area of adult social care is one where law and policy intermingle and overlap to such an extent it is sometimes difficult to tell one from the other. The line is blurred further by regulation and a compliance regime designed to promote policy that reflects accepted best practice.

For the purposes of this paper, it is necessary to concentrate more on policy and best practice as the law is mainly concerned with entitlement to services rather than how those services are delivered. It is important to note, however, that new legislation on health and social care will be influenced by policy on the greater personalisation of care services and the development of prevention services which rely upon greater integration of health and social care services. The new adult social care legislation's focus on personalisation combined with a greater emphasis on joint strategic needs analyses by the new health and wellbeing boards created under the Health and Social Care Bill will provide more statutory detail about the way that care should be commissioned and delivered (House of Commons Bill, 2010-2011).

Commissioning

Adult social care policy is formulated centrally and locally and then implemented through the commissioning relationship between local authority and care provider through a number of mechanisms.

As part of the contract for services to be delivered by a provider, the commissioner will require that particular standards of care are met. These may be expressed as compliance with care standards issued from time to time by the regulator and/or in broad terms contained within service specifications such as 'dignity and privacy', 'individualised care plans' or 'personalised services' that have become common terminology but which do not have a single agreed definition. Contracts will be monitored by commissioners through site visits and a reporting mechanism. Commissioners and social services departments will also respond to complaints about services.

Contracts provide recourse for remedying breaches of standards of care that are required either expressly or implicitly through the commissioning relationship. If breaches are not remedied or are so serious as to trigger a need for immediate action, contracts can be suspended or terminated. The right of a contracting authority to enforce a standard of care through the threat or actual suspension or termination of a contract is a tool that is probably as powerful as regulation because of the financial consequences of such actions on providers.

Commissioning and safeguarding

The relationship between contractual enforcement and safeguarding vulnerable adults forums is closer than perhaps was envisaged when *No Secrets* was published by the Department of Health (Department of Health, 2000). Despite the importance of the principle of safeguarding, the unstructured development of safeguarding committees and policies has led by default to a conservative approach towards risk as viewed by local authorities.

It is almost inevitable that a committee set up to protect against abuse will look for abuses against which it must protect. This had led to local differentiations on the definition of abuse but in general the scope has been broadened to encompass most if not anything that could – either deliberately or through permissiveness – put people at risk of harm. Unfortunately, this discourages a more progressive approach to risk that is in line with policy on encouraging service users to make their own decisions and life choices and to become more independent.

The mere fact that a safeguarding investigation is initiated in relation to a provider’s care practices will count against a provider. In cases of repeated referrals or greater perceived seriousness of a situation, care commissioners will be alerted and may take action to suspend a contract until assurances are provided that services are being delivered within the authority’s vision. Where there is a divergence of views on the approach to care, the power balance will usually favour the authority.

To suggest that authorities are always in the wrong is not at all correct. There is a broad spectrum that covers adult social care providers, in terms of their approach to care, risk and autonomy. The Care Quality Commission’s (CQC’s) regular state of care reports reflect examples of good and poor practice in the delivery of personalised care and the development of independence within service users. Where providers do not promote independence and risk-taking by individuals (whether this is due to a lack of understanding of policy and best practice, the inability of management to implement best practice, or simply convenience) safeguarding committees, backed up by the weight of their contracts departments, can play a positive role in forcing them to adopt more progressive care practices. I have advised in a number of cases where safeguarding committees have been involved – including some where providers have put people in ‘bucket’ chairs from which they can’t get out, or excessively used bed rails to avoid people being a nuisance to others or wandering in a home – where clearly the committee was right to intervene and demand changes to care practices and improvements to care governance.

Thus, safeguarding committees play an important role in driving up the minimum standard of service user experience but are weaker when it comes to ‘letting go’ and in their interactions with providers who are more liberal than them.

Commissioning, safeguarding and regulation

The various agencies that have statutory roles in overseeing the provision of care services share information with each other so that they can better fulfil their objectives and work jointly to promote and protect positive care experiences. In theory, this presents no problem. However, where the regulator and social services department have a similarly conservative approach to risk their combined force will act as a greater inhibitor to care services that want to promote greater risk taking.

Local authorities and regulators have a different relationship with service users and this, in the longer term, will influence how they develop their approaches to risk. As a service regulator, the CQC looks at individual examples of care to judge the overall performance of the provider but it is not really concerned with the individual themselves. In contrast, local authorities have a direct duty of care to service users and, in consequence, the behaviour of the local authority is sometimes more paternalistic towards, and protective of, the individuals receiving care. Professional regulators such as the Nursing and Midwifery Council and the General Social Care Council (whose functions are to be transferred to the Health Professions Council as part of the government’s review of arms-length bodies) also have a role. These bodies will scrutinise the professional conduct of their individual members and take action against them if their practices negatively impact on service users.

These distinctions may appear subtle, but they can be powerful. For example, I may be more liberal in my attitude to what parents in general should allow their children to do than I am prepared to be with my own children, for whom I feel naturally more protective. This should be coupled with the direct risk of litigation and negative press in the event that an individual comes to harm; it can be seen how the different relationships may lead to different behaviours and thresholds for intervention.

The role of adult social care regulation

When we talk of regulation within the adult social care sector, we generally mean that which is within the function of the CQC under the Health and Social Care Act 2008. However, not all adult social care is regulated by the CQC.

The main types of care that are subject to regulation include care homes, domiciliary care, some supported living, residential special schools and colleges, and shared lives-type schemes. Those care services that fall outside the scope of CQC regulation are nevertheless regulated in the wider sense through their contracts with commissioners and through safeguarding (see above), although there is a gap if non-CQC regulated services are paid for privately, for example some forms of extra care or supported living within retirement villages. Residual regulation is provided through schemes such as health and safety, which is concerned with the management of risk and the reduction of harm, if less so with the promotion of positive care practices.

Risk plays a major part in the language of social care regulation and the attitude of the regulator to compliance on risk is an important factor in determining whether risk practices are promoted in a liberating or restrictive manner. While the regulator does have a role in preventing unacceptable risks to the health and well-being of service users, positive risk-taking should not be hindered by the regulatory regime taking a cautious approach to care. The regulator needs to be sensitive to the fact that individuals and families may want to take or accept risks in the course of the service user's enjoyment of their everyday life. This makes service provision both challenging and fulfilling and providers should not necessarily have to look over their shoulders in fear of regulatory disapproval when they are actually enhancing the lives of people. Indeed, an overtly cautious regulator could be accused of adopting practices that restricted the rights of individuals to enjoy autonomy and the right to privacy and could be subject to judicial review of any that were deemed to breach the service user's human rights which protect these fundamental choices.

Alternatively, if the regulator adopts a positive approach to risk, then it can actually enable risk-taking and promote personal freedoms, such as by doing the following:

- having requirements for service providers to explore expanding service users' horizons
- being clear that action will not be taken against a provider where risk was appropriately managed, but nevertheless a negative consequence occurred
- rewarding those providers who encourage service users to partake in activities where the risk is appropriately managed
- educating inspectors/the regulator about how the court views too paternalistic an approach.

The rights of the individual

The dictionary defines rights as 'a moral or legal entitlement to have or do something' (Oxford English Dictionary, 2nd ed). Legal commentators, when thinking about rights in a legal sense, have stated 'in describing a right "in a strong sense", the status of a right therefore entails that a person both is entitled to stand on his own right and to require others to be duty bound to respect it'. (The Law of Human Rights, Vol 1, 2nd ed). This phrase is generally interpreted in society to mean that everyone is entitled to live their life in the manner that they choose, subject to the rights of others in society.

The most obvious source of an individual's rights is the European Convention for the Protection of Human Rights and Fundamental Freedoms (1950) (ECHR) which has been given effect by the Human Rights Act 1998 (HRA). However, rights in English law also derive from a number of other sources. For example, from other statutes such as section 48 of the National Assistance Act 1948, which imposes a duty on local authorities to maintain people's property when they are in hospital and also from common law which provides citizens with protection from the state, for example the doctrine of habeas corpus (the protection from unlawful detention). Additionally, certain people are owed a duty of care by organs of the state and others (also known as the law of tort), and the law of contract protects those who enter into agreements in certain circumstances.

Human rights and social care

The rights conveyed by the ECHR are multifarious, ranging from the right to life (Article 2) to the right to assembly (Article 11). Those which apply most directly in the context of social care, as per the scope of this paper, are:

Article 3 – **the right not to be tortured or treated in an inhuman or degrading way**. At the extreme, severely limiting someone's access to normal facilities or interactions may be inhuman or degrading. For example, the excessive use of mechanical restraints, including specially designed chairs, or bed rails, for long periods of time with no overriding therapeutic purpose could be inhuman or degrading. (See for example the institutional abuse identified in various facilities in and around Budock Hospital in Cornwall where people with learning disabilities were found strapped to wheelchairs for excessive periods. A joint investigation by the Healthcare Commission and Commission for Social Care Inspection (Commission for Social Care Inspection and Healthcare Commission, 2006) found over 64 incidents of abuse over the five years leading to October 2005. Some of the worst abuse occurred outside the hospital, in houses where up to four people lived with support from NHS carers. The inspectors said that more than two-thirds of the houses placed unacceptable restrictions on their residents).

The definitions applied by the joint project between the Department of Health and the British Institute for Human Rights (Department of Health, 2008) defines inhuman treatment as treatment causing severe mental or physical suffering and degrading treatment as treatment that is grossly humiliating and undignified. The potential scope of Article 3 is much wider than physical interventions and includes care that falls grossly below the acceptable standards of ensuring that people live in a dignified manner within a care home.

Article 5 – the right to liberty in social care has been promoted through the implementation in April 2009 of enhanced safeguards introduced by the Deprivation of Liberty Safeguards (DoLS) within the Mental Capacity Act 2005. It is too early to judge the practical impact of the DoLS regime, but in theory providers should have audited care practices to ensure that the right to liberty enjoyed by service users was not unlawfully interfered with otherwise than with a formal authorisation from the relevant supervisory body (a local authority or PCT), and that the individual circumstances of the deprivation of liberty were in the person's best interests. There has been a spate of recent case law (analysed most recently in the Court of Appeal case of P & Q v Surrey County Council [2011] EWCA Civ 190) on what amounts to a deprivation of liberty, the detail of which falls outside the scope of this paper, but which recognises that there will by necessity be some generalised restrictions on liberty within the provision of social care which is lawful, but that this must not become a deprivation of liberty without proper DoLS authorisation.

It is worth noting that the concept of best interests in this context would incorporate positive aspects of risk-taking, such as facilitating freedom of movement by service users even though there are associated risks. Risk, in and of itself, is not a justification for deprivation of liberty. For a deprivation of liberty to be lawful, it would have to be necessary as the only proportionate way to manage the risk presented by someone to themselves or others.

Article 8 – see below for a detailed analysis

Article 14 – the right not to be discriminated against is not a freestanding right but attaches to the manner in which other Convention rights are enjoyed. Therefore it would be unlawful to discriminate against someone because of their age or disability in the manner in which they were able to make choices about their private life or live in a dignified way. In order to establish discrimination, it is necessary to show that the person is being treated differently compared with others in a similar situation.

Article 8

(Recommended on this subject is Mr Justice Munby's paper for the Social Care Institute for Excellence (Munby, 2006) on article 8).

One of the most recognisable and important rights is Article 8 which enshrines the right to a private and family life, home and correspondence. This appears to be quite specific but has been interpreted to be wide ranging, including 'physical or bodily integrity; personal identity and lifestyle (at least in some respects), including sexuality and sexual orientation; reputation; family life; the home and home environment; and correspondence, embracing all forms of communication' (Lester, Pannick and Herberg, 2009, pp. 359).

In seeking to assert the breadth of Article 8 the European Court of Justice stated in *Pretty v United Kingdom* ([2002] 3*5* EHRR 1 at para [61]):

> *... the concept of `private life' is a broad term not susceptible to exhaustive definition. It covers the physical and psychological integrity of a person. It can sometimes embrace aspects of an individual's physical and social identity ... Article 8 also protects a right to personal development, and the right to establish and develop relationships with other human beings and the outside world. Though no previous case has established as such any right to self-determination as being contained in Article 8 of the Convention, the court considers that the notion of personal autonomy is an important principle underlying the interpretation of its guarantees.*

Personal autonomy is crucial to self-determination in matters such as risk-taking behaviour and the acceptance of risk as part of living life in a fulfilling manner.

Article 8 is not an absolute right. Infringements of this right can be lawful, and clearly must be if we are to live in a society where people must temper their desires so as not to affect others. Any infringement must be proportional. Many have been quick to point out the limitations of the Article 8 right; it has been said that 'Article 8 is not direct to the protection of property interests or contractual rights. Article 8 does not, in terms give a right to be provided with a home and does not provide a freestanding right to a clean and quiet environment' (Lester, Pannick and Herberg, 2009, pp. 360, footnotes 13/14/15). However, it is agreed that '*Individuals should have an area of autonomous development interaction and liberty, a 'private sphere', with or without interaction with others free from state intervention and free from excessive, unsolicited intervention by other uninvited individuals'* (Lester, Pannick and Herberg, 2009, pp.359), and that '*At the heart of the right to privacy lies the notion of personal liberty and autonomy* (Clayton and Tomlinson, 2009, pp.1006, footnote 4).

Historically the enforcement of Article 8 by the courts has been as a negative obligation placed on the state, i.e. to stop infringing someone's Article 8 rights, for example the state cannot criminalise certain forms of consensual sexual activity. However it is increasingly being interpreted as a positive obligation, to make the enjoyment of Article 8 rights real and substantial.

In the case of A*, B, X and Y v East Sussex County Council* ([2003] EWHC 167 (Admin))the Court considered a local authority's obligations to engage in the manual handling of service users as was necessary to allow them to enjoy their Article 8 rights. The key principles for employers and service providers to emerge from the decision are:

- Health and safety law does not require a guarantee of absolute safety of employees – the employer's obligation is to avoid or minimise the risk to staff *so far as is reasonably practicable*.
- In the context of care arrangements for people with disabilities, their human right to dignity, independence and participation in the community, as protected by Article 8 of the European Convention on Human Rights must be taken into account when assessing risk.
- When assessing the impact on the disabled person, the following must be considered, though none are determinative, in a user-focused way: the physical and mental characteristics of the person, the nature and degree of disability; the wishes and feelings of the person, and negative reactions to proposals. Prolonged resistance, and obvious great distress may make it impracticable to avoid manual lifting.
- A balance must be struck between the needs and rights of service users and the needs and rights of carers – the one does not take precedence over the other.
- In striking that balance matters of dignity and respect weigh heavily with people who are already shut out from so much of what makes life enjoyable and enriching for the majority of society.
- There will be situations in social care where manual lifting, even though it entails a real risk of injury to the care worker, is inherently necessary when providing an appropriate adequate care package which takes accounts of the needs and human rights of service users.

(Schwher, 2004)

The court found that it would be unlawful to have a blanket policy on lifting which limited the rights of service users to be moved to emergency situations or only times when a hoist was available. The judge went further to give practical examples of what the courts would consider to be unlawfully restrictive:

> *A and B's rights to participate in the life of the community and to have access to an appropriate range of recreational and cultural activities are so important that a significant amount of manual handling may be required. Thus it is likely to be unlawful for a carer:*

a) to fail to take them out of the house (for example for a swim) merely because a power cut means that the hoist is not working, or
b) to restrict the time available for access to such activities as shopping, swimming and horse-riding because manual lifting would otherwise be required, or
c) to fail to take them swimming once or twice a week because the swimming baths do not have a hoist, or
d) to fail to take them shopping because changing their incontinence pads requires manually lifting them.

Providers must strike a balance between their obligations to their employees and their obligations to service users, but there is a clear expectation that the state and its agents will be expected to take active steps to promote the rights of those in receipt of care so as to allow individuals to lead a fulfilling life. (The obligation on local authorities and PCTs extends to all care provision – in A, B, X and Y the claimants lived at home and were in receipt of complex care packages).

Vulnerable adults who have capacity are outside the protection of the Court of Protection (which makes decisions for those who lack capacity with regard to property, financial affairs, healthcare and personal welfare) but have some residual protection through the inherent jurisdiction of the Family Division of the High Court which was held in *RE SA (Vulnerable Adult with Capacity: Marriage)* [2005] EWHC 2942 (Fam), [2006] 1FLR 867). ('Vulnerable' is used in the context of the Safeguarding Vulnerable Groups Act 2006, i.e. those who are using care services. This group is analogous to that defined by *No Secrets* [Department of Health, 2000] as vulnerable and therefore in need to protection through safeguarding practices). In *St George's Healthcare NHS Trust v S; R v Collins and others, ex parte S* [1998] 3 All ER 673, a pregnant woman with pre-eclampsia refused consent to have the birth of her child induced and to have a caesarean section as she wanted a 'natural birth'. The woman was admitted under section 2 of the Mental Health Act 1983, a declaration was sought that she could be provided with treatment against her wishes and she underwent a caesarean section. She subsequently challenged her treatment and it was held that the hospital had acted unlawfully. The woman was mentally competent to make the decisions she did and understood the risks; she was therefore entitled to refuse medical treatment. This principle applies across society – anyone who has mental capacity is entitled to make their own personal choices about their life provided they act within the law and insofar as those choices do not unlawfully breach the rights of others.

What does this mean for those in adult social care?

As informed and articulate adults leading independent lives, we are the first to complain when our rights are being threatened or infringed. We know that we can contact a solicitor or talk to a newspaper when we feel aggrieved. However many of those in adult social care, whether or not they have mental capacity, do not have it within their means to take such action. It is a crucial part of care provision that those making decisions for or on behalf of vulnerable adults need to take into account their Article 8 rights, something that is easy to say but which needs to be embedded within the culture of care.

When considering the influence of Article 8 in decision-making, Lord Justice Munby has stated that:

> *The fundamental point is that the public authority decision making must engage appropriately and meaningfully both with P and with P's partner, relatives and carers. The state's obligations under Art 8 are not merely substantive; they are also procedural. Those affected must be allowed to participate effectively in the decision-making process. It is simply unacceptable – and an actionable breach of Article 8 – for a local authority to decide, without reference to P and her carers, what [is] to be done and then merely to tell them – to 'share' with them – the decision.*
>
> *Fundamental to the process of properly engaging P in the decision-making process is listening to and taking account of P's wishes and feelings. The fact that P lacks the relevant capacity does not mean that her wishes and feelings simply fall out of account.*
>
> *It is elementary that decisions are made by reference to the vulnerable adult's best interests. It is equally elementary that in determining where such an adult's best interests truly lie, it is necessary, just as in the case of a child, to have regard to his wishes and feelings, whether verbalised or articulated or not. [*See for example Re M, ITW and Z [2009] EWHC 2525 Fam]. *As Hale LJ [Lady Justice] (as she was then) once observed: 'The wishes and feelings of the incapacitated person will be an important element in determining what is, or is not, in his best interests. Where he is actively opposed to a course of action, the benefits which it holds for him will have to be carefully weighed against the disadvantages of going against his wishes, especially if force is required to do this.*'
>
> *(Munby, 2010)*

How far does this right go?

While the quotation from Lady Justice Hale describes a situation where a vulnerable person is opposed to a course of action, the reverse is also true (i.e. their wishes should be facilitated) where an individual seeks to take a course of action to which their carers might be opposed, within limits.

The ECHR requires that any interference by the state for the protection of an adult in social care must be for a legitimate aim, usually the protection of welfare and interests, and that it must be necessary in a democratic society. This is essentially the well-known legal doctrine of adopting a proportionate means to achieve a legitimate aim. While this is true, it implies a minimisation of risk for those in adult social care. However, the reverse can again be true. Decision-makers can only interfere with a vulnerable adult's rights to a proportionate degree when preventing them from taking an action of their choosing. After all, welfare extends beyond physical safety, and extends to the fulfilment of the potential of each person's social functioning (see for example the A, B, X and Y case mentioned above).

The application and limits of human rights in adult social care

It is important to remember as a general rule of thumb that the ECHR and the HRA are limited to protection from those rights being infringed by the state, and not the private sector and individuals. As the social care sector is dominated by privately owned or third-sector organisations, rather than the state, often – and until very recently – the HRA has had more limited relevance in care provision outside of that provided directly by local authorities.

In a judgment given in early 2007 (YL (by her litigation friend the Official Solicitor) (FC) (Appellant) v. Birmingham City Council and others (Respondents)[2007] UKHL 27), the House of Lords found that a private care home providing accommodation to elderly residents is not bound by the ECHR when providing such care on behalf of a public authority. However, the government responded by enacting legislation that included a provision specifically intended to broaden the remit of human rights law in social care. Section 145 of the Health and Social Care Act 2008 states:

> *145*
> *Human Rights Act 1998: provision of certain social care to be public function*
>
> *(1) A person ('P') who provides accommodation, together with nursing or personal care, in a care home for an individual under arrangements made with P under the relevant statutory provisions is to be taken for the purposes of subsection (3)(b) of section 6 of the Human Rights Act 1998 (c. 42) (acts of public authorities) to be exercising a function of a public nature in doing so.*
>
> *(2) The 'relevant statutory provisions' are —*
>
> *(a) in relation to England and Wales, sections 21(1)(a) and 26 of the National Assistance Act 1948 (c. 29),*
>
> *(b) in relation to Scotland, section 12 or 13A of the Social Work (Scotland) Act 1968 (c. 49), and*
>
> *(c) in relation to Northern Ireland, Articles 15 and 36 of the Health and Personal Social Services (Northern Ireland) Order 1972 (S.I. 1972/1265 (N.I. 14)).*

The important effect of this new enactment is that where residential accommodation is being paid for by local authorities the HRA will be enforceable against any provider, including the private and voluntary sector, which werepreviously not public authorities for the purpose of enforcing the HRA. However, the extension of the HRA to the private and voluntary sector by section 145 of the Health and Social Care Act 2008 only applies where the accommodation is arranged under the provisions in subsection 2. That means, in England, that the extension of the HRA does not give any enhanced protection to people whose care is arranged by a PCT (for example under continuing health care funding) or is privately funded.

It is therefore possible for a care home to be a public authority in respect of some residents but not for others, depending on how they are funded. It does not appear to be the case that if a care home is caught for some residents it is caught for all because the statutory language seems to link the public function to *individuals*: ‘A person (“P”) who provides accommodation, together with nursing or personal care, in a care home for an individual... is to be taken … to be exercising a function of a public nature’

If this is correct, it seems to be blatantly discriminatory and ripe to be challenged by a test case in the courts. However, and in any event, it has been reported by the British Institute of Human Rights that the positive aspects of the new legislation are being lost because care providers are not being informed about their new obligations to comply with human rights (Samuel, 2011)

It may be that this is the case but I would suggest that this should not have too great a short-term impact in everyday outcomes for service users because of the statutory obligations placed upon care providers by the legislation and standards issued under the Health and Social Care Act 2008. These ought to be interpreted in a manner which confers the same safeguards for individuals as the Human Rights Act protects. I do accept, however, that tangible benefits can be gained through the development of a culture of human rights within independent sector care services, as was experienced in the public sector following the enactment of the Human Rights Act in the year 2000.

Enforcing human rights

There are a number of ways to enforce human rights. The easiest way is to remind a provider of its obligation to provide services in a way that is compatible with the human rights of service users. All providers, regardless of their funding streams, are required by CQC’s Essential Standards of Quality and Safety (see below) to promote and protect dignity and autonomy, so in this respect (i.e. the practical if not the fundamental) the rights of all social care residents – or users if not in care homes – are similar.

As mentioned above, commissioners are obliged to commission services in a manner that promotes and protects human rights. If an individual or their family are not satisfied that a service is complying with their rights, they can complain to the funding authority, if there is one (so again, here, there is a fundamental difference in the availability of rights for state and privately funded individuals).

An aggrieved individual may complain to the regulator which could lead to an investigation or inspection to look at the circumstances of the complaint to ensure that standards of care were in line with regulatory obligations.

If a person feels that they are being discriminated against, it is possible that they could complain to the EHRC which will then look at the practices being adopted, although it is not the role of the EHRC to provide remedies in individual cases.

Finally, it is possible for an individual to bring a direct action against a public authority care home provider or private and voluntary sector care home provider caught by section 145 of the Health and Social Care Act by an application to court. Such an action could be directly under the Human Rights Act, or could be by way of judicial review if the complaint is about the manner in which a decision about a care service was made rather than the substance of the care.

In any analysis of a care provider’s practice, the scrutineer (be that a judge, a regulator, commissioner, or the provider itself) ought to have regard to what was reasonable and practicable within the circumstances. So, it will not in most cases be necessary for a provider to go to great lengths to satisfy a person’s wishes if there would be a heavy cost or knock-on effect to other parts of the service. Here lie the limits of personalisation and individualised care – it must be looked at in the context of the overall service provision. This is not to say that a ‘resources’ argument can have a blanket effect. There ought to be some balancing of available resources against the need to go some way to providing individualised care.

There are basic standards of care, dignity and autonomy that provide a minimum threshold for acceptable standards of care and should never be breached. For anything above the basic standard, it will be necessary to adopt tests such as reasonableness, best practice, proportionality, and also to consider financial costs and other resources at times (such as now) when funding for services is tight.

As well as human rights, privately funded individuals, and those exercising personal budgets, should consider their consumer rights to ensure that the standard and description of services accords with that they bargained upon when accepting a care and/or accommodation package or, in the case of top-up arrangements, the part of the package for which they felt enticed into paying more. This might indeed be a more effective way of securing redress than contemplating a human rights-based claim.

Risk, informed risk and others’ rights

Do a person’s rights extend to taking risks? If so, do those in adult social care have the same right to take risks as people who are not in receipt of care?

Almost any human endeavour carries some risk, but some are much more risky than others. The dictionary defines the primary meaning of risk as ‘a situation involving exposure to danger’ and further, ‘a person or thing regarded as likely to turn out well or badly in a particular context or respect’ (Oxford English Dictionary, 2nd ed).

It has been argued that ‘contemporary society is no longer primarily concerned with attaining something “good” but with preventing the worst, with the result that self-limitation, as opposed to self-realisation, becomes the goal of both the individual and society’(McLaughlin, 2007).

‘Informed’ risk implies very much that an individual understands at least the main consequences of the risk they are seeking to take. Therefore for a person to be able to take an informed risk they must have mental capacity. Going further, informed risk also implies a level of responsibility a person takes for their own actions, and an understanding they may be held to account. There cannot be an expectation that this burden can apply to those who lack capacity but does this necessarily mean that unless a person can take responsibility for their own actions they cannot take risks? Such a situation would impose a very limited range of life experiences for those who lack capacity. It should be noted that there is a range of decisions that people are faced with as part of their everyday lives, some of which they may have capacity to decide, others (usually the more complex ones) which they will not. Providers must be careful not to adopt a blanket approach to capacity.

Individuals' choice to take risks is most likely to affect others when they enter residential care. If an individual does have capacity when they enter a care home, they will be required to sign a contract to state that they are prepared to comply with the rules of the establishment. This seems like the most sensible approach for those effectively entering a new community, and mostly works well. The consequences of a person with capacity causing harm to another through their risk-taking could be criminal – after all recklessness is often an element in many criminal offences – or being ejected from the community they have joined.

What is much more difficult is where the person causing harm lacks mental capacity in this regard. The usual consequence is that the person is deemed to have 'challenging behaviour' and therefore their needs are not being met, and they are moved to a provider who better caters to those needs. This can often be a positive step; such providers have a greater understanding of conditions that can result in challenging behaviour, such as autism. However there may be a greater chance of the individual's freedoms being further curtailed.

At the heart of this is what constitutes an *acceptable* risk? Is this something to be determined by the individual taking the risk or by providers and regulators deciding what is appropriate? Surely this would go against the movement for greater choice and self-determination. If it is for the individual to decide, how is this approached if they do not have capacity? Should people receiving care be allowed to make bad decisions? For example, alcoholics who insist on continuing to drink: this is both self-destructive behaviour and can affect those who share the residential placement; however if the person has the funds to do so and the capacity to make this decision should they not be allowed to continue?

Nothing Ventured, Nothing Gained: Risk Guidance for People with Dementia (Department of Health, 2010a) is a step forward in accepting that risk is an important part of care, which should be embraced rather than avoided. It focuses heavily on risk enablement strategies and encouraging people to talk about and accept risk. It does not have a heavy emphasis on human rights, but looks at practical issues and consequences where rights are inherent. It is an excellent source of reference for academic studies in this area, one of which interestingly highlights the role of defensible strategies in managing risk that would allow providers to justify their practices:

> *An action or decision is deemed defensible if an objective group of professionals would consider that:*
>
> - *all reasonable steps have been taken*
> - *reliable assessment methods have been used*
> - *information has been collated and thoroughly evaluated*
> - *decisions are recorded, communicated and thoroughly evaluated*
> - *policies and procedures have been followed*

- *practitioners and their managers adopt an investigative approach and are proactive.*

(Kemshall, 2009)

The nature of an acceptable risk and how to facilitate it has recently been explored in the courts further in *D Local Authority v AB* [2011] EWHC 101. AB was a man with a moderate learning disability who was engaging in a sexual relationship with another man accommodated with him. The local authority sought a declaration that A did not have capacity to consent to sexual relations. The court held that A did not have an appreciation of the health risks involved, and therefore did not have the capacity to consent to sexual relations. However, interestingly, the court refused to grant a final declaration and instructed the authority to put in place educational measures to assist A to acquire capacity. This went against the opinion of the expert who believed it would not be in A's best interest to undertake the educational measures as this was likely to confuse and upset him.

Where we have got to with regulation?

We are a highly regulated society, but why is there so much regulation? The Better Regulation Commission (now abolished) in its 2006 Report *Risk, Responsibility and Regulation – Whose Rsk is it Anyway?* (Better Regulation Commission, 2006) identified a regulatory spiral whereby:

> *The perception of a risk emerges. This can be progressive over time, such as the risks of obesity, or following a specific incident, such as the kayaking accident in Lyme Regis in 1993;*
>
> *1. A public debate follows, often based around headlines and incomplete or biased information, resulting in a call for 'something to be done', which is amplified by the media;*
> *2. Instinctively, the public looks to the government to manage the risk.*

However, in the last 10 years the then Labour Government tried to move away from knee-jerk regulation and take a different approach to risk and regulation and redefine the approach to risk management by:

- *emphasising the importance of resilience, self-reliance, freedom, innovation and the spirit of adventure in today's society*
- *leaving the responsibility for managing risk with those best placed to manage it and to embark on state regulation only where it represents the optimum solution for managing risk*
- *re-examining areas where the state has assumed more responsibility for people's lives than is healthy or desired*
- *separating fact from emotion and emphasising the need to balance necessary levels of protection with preserving reasonable levels of risk.*

(Better Regulation Commission, 2006)

While no one disputes that adult social care should be regulated, given that it deals with some of the most vulnerable people in society, there is clearly a question as to whether and to what extent regulation impedes risk taking in those it seeks to protect. The purpose of regulation in this sector must be fundamentally pinned by each care recipient's human right to fulfil their human potential.

The CQC has produced regulatory guidance that providers are expected to follow: *The Essential Standards of Safety and Quality*. This supersedes the National Minimum Standards made under the Care Standards Act 2000 and form the basis for the current regime of assessment and inspection.

The key regulation relating to encouraging the *involvement* of service users is Regulation 17 of the Health and Social Care Act 2008 (Regulated Activities) Regulations 2010 – Respecting and Involving Service Users:

(1) The registered person must, so far as reasonably practicable, make suitable arrangements to ensure –
    (a) the dignity, privacy and independence of service users; and
    (b) that service users are enabled to make, or participate in making, decisions relating to their care or treatment.
(2) For the purposes of paragraph (1), the registered person must –
    (a) treat service users with consideration and respect;
    (b) provide service users with appropriate information and support in relation to their care or treatment;
    (c) encourage service users, or those acting on their behalf, to –
        (i) understand the care or treatment choices available to the service user, and discuss with an appropriate health care professional, or other appropriate person, the balance of risks and benefits involved in any particular course of care or treatment, and
        (ii) express their views as to what is important to them in relation to the care or treatment;
    (d) where necessary, assist service users, or those acting on their behalf, to express the views referred to in sub-paragraph (c)(ii) and, so far as appropriate and reasonably practicable, accommodate those views;
    (e) where appropriate, provide opportunities for service users to manage their own care or treatment;
    (f) where appropriate, involve service users in decisions relating to the way in which the regulated activity is carried on in so far as it relates to their care or treatment;
    (g) *provide appropriate opportunities, encouragement and support to service users in relation to promoting their autonomy, independence and community involvement*; and
    (h) take care to ensure that care and treatment is provided to service users with due regard to their age, sex, religious persuasion, sexual orientation, racial origin, cultural and linguistic background and any disability they may have.

(author's italics)

This appears positive, although what amounts to an ‘appropriate’ opportunity is open to interpretation. Hopefully this will be construed as widely as the circumstances require rather than in a blanket manner, requiring a subtler type of regulation than we have seen at times.

The language used within the regulation reflects some of the language we have seen coming out of the courts as highlighted earlier, especially the need for autonomy, independence and community involvement. Interpreted in a facilitative way, the regulations have every potential to encourage providers to deliver care in a manner that enables risk-taking as a way of ensuring that service users effectively engage with the world outside themselves and make their own choices about their personal life. This will require differing levels of risk management and risk acceptance along the way, evidenced through assessments and descriptions of personal choice agendas. Good practice requires this anyway, but it will be interesting to see how openly CQC interprets the regulations and allows permissive practices as part of good care (in the right circumstances).

Many would say that there is a need for greater information and training provision about the interface between care, autonomy and other essential rights that should be increasingly embedded in everyday care practices. Part of good provider governance is knowing (a) what the best practice requires, (b) what the commissioner requires is different and providers need help in understanding how to fulfil their responsibility to promote rights. Such help should be readily available from commissioners and regulators through guidance and contract specification or supervision in the interests of service users, and providers should be encouraged to further develop care practices without fear of penalty.

Conclusion

It is important that adult social care promotes and protects the rights of individuals to live fulfilling lives. However, it is not necessarily going to be comfortable for the state to look on while vulnerable people are allowed to make choices that create risks to themselves, and possibly others.

As is often the case, this complex dynamic requires the balancing of risk against benefit and the tools that are available to the state (commissioning pressures, safeguarding interventions and regulatory enforcement) should be utilised proportionately, something which is easier said than done.

This is particularly true because:

- we do not have a uniformly good standard of service providers
- regulators often base their approach on tackling the worst rather than promoting the best
- the more hands-off approach to regulation by CQC does not allow providers to prove their credentials in promoting positive risk-taking
- there is a fear of litigation and reputational damage.

One essential way to start bridging the gap between risk and protectionism is to have a positive approach to human rights in social care. The concept of human rights should be asserted as that which underpins the structure of modern social care but in order to do that there is still some way to go. Organisations such as the British Institute of Human Rights, the Equalities and Human Rights Commission and the Social Care Institute for Excellence should work with government and key stakeholders such as the CQC and purchasers to develop our understanding of what is best practice – ideally without being too prescriptive so as not to scare providers. This ought to be approached as a medium-term project to maximise outcomes.

If adult social care is to embrace risk as a necessary part of care, it must develop the evidence base to hold up to regulators and safeguarding committees. The Department of Health guidance on risk in dementia services*, Nothing Ventured, Nothing Gained: Risk Guidance for People with Dementia* (Department of Health, 2010a) is a positive example of how stakeholders can work together to promote risk enablement. Other areas in care should learn from it and develop their own approaches.

The purpose of this paper has been to try to stimulate thought and debate about whether we are doing enough and what more we can do to translate law, policy and practice in a way that always places the dignity and autonomy of the users of care services at the heart of those services they use and engage with. JRF can and should be among the key stakeholders in identifying and championing current best practice and supporting the development of a rights-based approach to care that will, by its very nature, improve the experiences of those who are vulnerable.

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