

**JRF scoping paper:  
Rights, responsibilities, risk and regulation**

# Changing societal attitudes, and regulatory responses, to risk-taking in adult care

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**September 2011**

This paper:

- explores the relationship between policy initiatives regarding risk-taking in adult care and its claim to reflect user experience;
- argues that these policy initiatives are driven by the imperative of rationalising risk management; and
- claims that such policies are not a response to user demand and that more research is needed to evaluate the attitudes of users of adult care to risk-taking.

**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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The JRF has supported this project to inform its own thinking and programme development. The facts presented and views expressed in this paper are, however, those of the authors and not necessarily those of JRF.

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## Key points

- The claim that policy initiatives regarding risk-taking in adult care are a response to user demand is not supported by research-based evidence. There is a need for ethnographic research to ascertain the attitudes of users towards risk-taking in adult care.
- Risk narratives used by policy-makers and professionals and expressed through policy statements remain external to the way in which care users interpret their circumstances.
- Regulatory responses to risk-taking are principally concerned with rationalising risk management practices, rather than with altering the behaviour of care users.
- Attitudes to risk in adult care are ambiguous and there is little reliable evidence that can help illuminate our understanding of user demand.
- The 'right to take risks' has little practical meaning for users of care. Users of care want to be taken seriously but not necessarily as risk-takers.
- Adult users tend to be defined as 'at risk' and therefore rarely endowed with the capacity for agency. They are therefore seen as people that need to be protected from, rather than encouraged, to take risks.
- The absence of user voice in the current discussion needs to be rectified through research focused on the lived experience of adults using care.
- More research is required to take into account differential perspectives towards risk-taking between younger and older users of care and between carers and family members.
- One of the major challenges facing the institution of adult care is to learn to accept the risk of tolerating the cultivation of a more flexible, informal user-centred relationship.

## Introduction

This essay is based on the following activity and research:

- literature review and web search
- analysis of recent official documents relevant to adult care
- interviews with 14 elderly users of care facilities
- discussions with 6 carers and managers involved in service provision
- analysis of policy developments in the light of broader cultural attitudes towards risk.

It is difficult to gain a balanced assessment of societal attitudes towards risk-taking in adult care. In particular, there is very little reliable research providing information on the attitudes of care users. Yet policy-makers continually act as if their programmes and initiatives are a response to what care users want. This trend is clearly illustrated

in relation to the often-cited claim that there is a demand for greater risk-taking in adult care.

Despite the proliferation of the risk discourse, most people do not interpret the choices they make or the decisions they take through deploying this narrative. During my discussions with older adults who require care and support, I was struck by the absence of any reference to 'risk', 'risk-taking', 'choice' or any of the terms that policy-makers use in relation to the management of adult care. During the course of an early afternoon discussion (in 2008) with four men aged 70 to 74 years, living in a non-residential care setting, these men expressed strong views about their 'rights'. The term 'rights' sometimes conveys ideas about control and decision-making and can be interpreted as indirect reflections on risk. But what these men were most concerned about was being taken seriously by their carers, relatives, and members of their community.

These men took exception to carers 'who don't listen', 'who barely remember our names', and who, as one put it, 'respond to everything I ask as unreasonable'. If there was a 'right' that they really felt strongly about it was the 'right to the occasional friendly face'. One of the men talked about the need for 'the same friendly face' in reference to the constant turnover of his 'personal' carers. The sense of powerlessness conveyed by these comments is symptomatic of a much wider problem: the gulf between the aspirations of the users of adult care and the assumptions of policymakers and experts. Although numerous studies point to the absence of the user voice in policy-led research, there seems to be little interest in making visible the lived experience of users of adult care. (There are some important and useful studies of users of adult care, e.g. Beresford, Shamash Forrest, Turner, and Branfield (2005). However the method of research adopted in these studies tends to rely on participants mobilised through user organisations and advocacy groups, and therefore they often fail to convey the perceptions and unprompted attitudes of the more typical users of adult care). The kind of field research carried out by Bowers, *et al.*, (2009) is required for a better understanding of risk-taking in adult care.

## **Social attitudes towards risk-taking in adult care**

Social attitudes towards risk-taking in adult care are difficult to assess. Now and again it is possible to gain insights into the views of carers; but almost everything that is said and done in relation to the issues associated with risk and regulation in an adult care setting has been dominated by the initiatives of policy-makers and the response of care professionals and researchers. Reports frequently represent the views of those receiving care through the medium of user groups, which, no matter how sincere and well-intentioned, tend to provide a heavily-scripted story based on their provider/advocacy role.

Nevertheless, a review of official statements and reports on adult care indicates that the authors self-consciously frame their proposals and initiatives as a response to the demands and aspirations expressed by service users. These documents frequently adopt the rhetorical strategy of claiming to reflect the voices of care users. Time and again, they repeat a variant of the phrase 'we listened to users...who told us what they want'. A 2006 report, *Making Choices: Taking Risks*, published by the

Commission for Social Care Inspection (CSCI), is paradigmatic in this respect. It claims that it 'draws heavily upon the experiences and views of older people using social care about staying independent and taking risks', and that 'older people tell us they "want a life" not just services and acknowledge that to achieve that may entail some risks' (CSCI, 2006, pp. V–VI)

*Making Choices: Taking Risks* contains numerous quotes from individuals to demonstrate that its analysis and proposals express the aspirations of service users. To give a few examples:

*Let's be more robust in confronting the reality of our longer lives. We are making choices for ourselves.*

*Age, in itself, is not a disability but it brings disabilities and we have to adjust ... We still want to be masters of our own destiny.*

*The people in the home said 'we can't let you go out as we can't take the risk that you might get run over.'* (CSCI, 2006, pp.1)

However, on closer inspection it appears that the first statement comes from a lecture by a university professor broadcast on the radio, the second quote is from the Chair of the Greater London Forum for Older People, and the third by a Commission for Social Care Inspection seminar participant. No doubt these individuals, along with the other voices cited by the CSCI, have something important to state, but their statements are hardly representative of care users. While these statements are strongly held, its advocates have no mandate or authority to claim that they are representative of a wider community.

The authors of these statements operate within the orbit of care professionals and policy-makers, and express the views of a narrow stratum of people who are not the typical members of the user community. Indeed the very language with which they communicate their aspirations is littered with the jargon and vocabulary used in policy discourse. It is difficult to avoid the conclusion that these are statements scripted – perhaps unintentionally – by interviewers and focus group facilitators. This is further illustrated by the following statement in the CSCI's report:

*Older people using social care told the Commission that, like other people, if they are to 'have a life' they expect to take some risks. They said that risks are different for each person and can change from day to day and throughout life so risks need to be shared and to be managed with them. Good person-centred assessment should respect people's rights and wishes and translate into flexible, responsive support that puts people firmly in the driving seat. They said that sometimes there can be conflicts about risk-taking between individuals and their carers or relatives – particularly where there are questions about a person's mental capacity. In addition, risk-averse public attitudes and media opinion can inhibit people from exercising choice.* (CSCI, 2006, pp.3)

It does not require a sophisticated capacity for rhetorical analysis to draw the conclusion that normal users of social care do not talk like this. Questioning whose

voice is being communicated is not a trivial matter. It may well be that adult users of care are ardently supportive of risk-taking and person-centred assessment; but at the moment this is principally a matter of speculation by the proponents of such policies.

Whatever the merits of current policies, they should not be conceptualised as a response to user demand. The positive attitude towards greater choice and risk-taking, or the personalisation of services communicated through official statements and reports, should not be interpreted as anything more than an expression of official aspiration. One example is that of personal budgets. In numerous official accounts, the provision of personal budgets to adult service users is represented as something that is highly desired and appreciated by their recipients (SCIE, 2010). No doubt if people are asked if they prefer a personal service to an impersonal one they will opt for the former. However there appears to be little evidence that there is anything approaching a consensus on this issue. Indeed numerous professionals involved in the delivery of care have told me that many of their clients are 'confused' about or 'disinterested' in managing their own personal budgets.

One senior manager involved in the provision of adult care believes that 'most personal budget holders tend to be young disabled people, not older people'. The view that younger users of care are more likely to value risk-taking and regard such activities as a source of empowerment is widely echoed by both carers and researchers (see for example Mitchell and Glendinning, 2007). Drawing on her experience as a care professional, one of my informants stated that she believes that 'older people generally are more worried about finding the right care', and in many cases want someone who is more 'competent' to decide for them. 'They don't want the fuss, they just go along with what they've got now', she observed. To substantiate her point, this woman stated that 'there are "virtual personal budgets" held by local authorities for individuals who don't want to make a choice or don't have a broker to help them with their choice'. Apparently her local authority 'then contracts for that individual with a care provider and pays the provider directly' (interview, 2011).

It may well be possible that this woman's remarks about the relative lack of enthusiasm for personal budgets are based on a unique set of circumstances. But they reveal that the claim 'they tell us that they want personalised budgets...' should be recognised as a claim, rather than accepted as universal fact. Another manager of home care services was less equivocal: service users 'don't have time to look for personal assistants', she told me. She claimed that none of her clients were interested in personal budgets and that, as far as she was concerned, such budgets were an 'imposition' on her work (interview, 2011).

Lymberry (2010) has called into question the tendency to present the reform of adult social care as 'the inevitable consequence of the changed expectations of people who use services'. He notes that 'much of the rhetoric of personalisation is underpinned by a supposition of the characteristics of service users', as 'not only willing' but 'also able to maximize control over their lives' (pp. 5, 16). Lymberry points to a process whereby the views and objectives of policy-makers are casually recycled as expressing the new or changed attitudes of care users.

It may well be that there is a significant degree of support for the personalisation of care. But without more evidence that this is indeed what users expect, one can only speculate. There is, however, some evidence calling into question the claim that there is a mass demand for personal budgets: this is their relatively slow take-up. 'It is a disgrace that only 13 per cent of adult service users in England have access to personal budgets,' stated the care services minister Paul Burstow in November 2010 (Smith, 2010). Burstow pointed the finger at unresponsive service providers – but just possibly, it may have been the relatively patchy demand that accounted for this state of affairs.

Policy-makers represent the personalisation of services as an issue of freedom. 'We want people to have the freedom to choose the services that are right for them from a vibrant plural market', states a recent report, *Vision for Adult Social Care: Capable Communities and Active Citizens*, adding 'that is why this vision challenges councils to provide personal budgets, preferably as direct payments, to everyone eligible within the next two year' (Department of Health, 2010, pp. 4). This is a far more accurate representation of the relationship between policy and social attitudes. The emphasis is on the assertion that 'we want people to have freedom', rather than the claim that 'people told us they want to be free of local authority control'. In this case there is a legitimate projection of a vision that contains the assumption that it is policy-makers, and not social attitudes, that are responsible for the personalisation agenda.

The advocacy of personalisation is paralleled by the promotion of a less bureaucratic and more liberal regulatory culture. Both of these policy innovations represent an attempt to deliver services in a more efficient and targeted manner. So the regulatory response to risk-taking in adult care is not principally about the extension of freedoms. It can be interpreted as an institutional reaction to the previous effects of a one-dimensional, inflexible managerial orientation towards the provision of care. For well over a decade, the perverse consequences of risk-averse policies in the public sector have been a focus of quiet concern (see for example Better Regulation Commission, 2006). In recent times, such criticisms of the inflexible practices of the Criminal Records Bureau have forced government to review its operations. Periodic outbursts of frustration against zealous rule-making and the regulation of everyday life are testimony to the widespread belief that greater flexibility is required in the domain of policy-making. Such sentiments are frequently reported in the media, and are widely held by significant sections of the public (for example such sentiments were frequently echoed during the course of my research carried out with volunteers about their perception of CRB checks (Furedi and Bristow (2010)). Policy-makers evidently believe that promising to 'reduce bureaucracy' will strike a chord with the public, which is why such undertakings are so regularly made.

However, from a sociological standpoint such periodic outbursts of frustration represent a backlash, rather than the projection of a serious alternative to regulation. While criticism of the risk-averse practices associated with the imperative to regulate often have a sound basis in the experience of social care, it is important to note that calls to reform adult care are often motivated by different institutional and financial concerns. The personalisation agenda is widely perceived as an attempt to make adult care cheaper and more efficient, and indeed that was the unprompted view of every care worker that I talked to. Confronted with the rising cost of adult care, policy-makers need to reconcile their proposals for reform with financial realities.

One of the unstated assumptions of such proposals is the belief that a greater openness to risk-taking will not only empower users of care, but also reduce the cost of these services for the Treasury. Risk-taking is frequently conceptualised as a means for institutionalising greater choice, which in turn will encourage the lowering of costs through the provision of services by more competitive providers.

The aim of this essay is not to question a specific policy initiative associated with the personalisation of care. It is merely to suggest that the idea that changing social attitudes drive care policy should not be taken as self-evident. From a sociological perspective, the absence of evidence about the attitudes of care users to risk-taking, choice, and the personalisation agenda is striking. Yet over the years numerous studies have noted the dearth of research into this subject (see for example Mitchell and Glendenning, 2003, pp. 3.) Given the tendency to rely on officially-sponsored and expert-led seminars for this kind of information, it is important to develop research strategies that draw on deeper ethnographic methods that can capture the unprompted, context specific responses of care users in situ (see Ray, Bernard and Phillips, 2009, pp. 13 on the importance of qualitative and biographical methods).

## How risk is conceptualised in relation to adult care

What has been observed in relation to the rhetoric surrounding personal budgets applies with equal force to risk-taking. Mitchell and Glendinning note that 'policies and practices concerning risk may appear irrelevant or misguided to some members of the public' (Mitchell and Glendinning, 2008, pp. 299). Most adults who receive care do not speak the language of risks. Although researchers have occasionally uncovered individual senior citizens who wish to run the London Marathon or go bungee jumping, most adults in care, and especially the elderly, do not harbour such aspirations. In our interviews with residents of nursing homes and individuals cared for at home, the emphasis was on gaining greater control over the conduct of everyday routine and not having to live according to an externally-imposed schedule managed by faceless individuals. While this response can be interpreted as a desire for greater personal choice the predominant sentiment that it expresses is an aspiration for routine, order and sensitive care.

Consequently the very conceptualisation of risk in relation to adult care has, in the first instance, been the outcome of policy deliberation and pragmatic concerns about the cost and quality of service delivery. There are a number of problems with the application of a risk narrative in adult care. **It is far from evident whether recent official advocacy of the right to take risks refers to altering the ethos of social care, represents a demand to modify the behaviour of carers, or constitutes a call to provide users with greater power to determine their lives.** When a key official document on adult care states that 'risk is no longer an excuse to limit people's freedom', the idea of more user autonomy and scope for the exercise of independence is conveyed (Department of Health, 2010, pp.8). But who is this exhortation addressed to? And what does the statement indicate about official attitudes towards risk? To answer these questions it is necessary to explore the meaning of risk within the context of adult care.

Time and again, studies of and reports on the subject of adult care acknowledge the fact that the concept of risk is used in a variety of different ways and that its meaning

is contested (Kemshall, 2002). And yet despite such qualifications, the term 'risk' is invariably used in a taken-for-granted manner. As one study noted, 'risk is used so frequently in discussions surrounding the care of older people that it is often treated as a relatively unproblematic concept' (Ray, Bernard and Phillips, 2009, pp. 36). To compound the confusion, policy statements and advice often express a contradictory sentiment between the formal affirmation of risk-taking, and an organisational disposition towards risk-avoidance. *A Vision For Adult Social Care* (Department of Health, 2010) conveys this sense of ambiguity towards risk. Outwardly it demands that concern about risk should not serve as an 'excuse to limit people's freedom'. But such a formulation betrays the belief that risk is something that people should be protected from, and hints of this negative framing of the concept recurs throughout the report. Its basic message is that the state should try not to be too overprotective and allow 'people to make decisions about risk without becoming intrusive or overbearing': associating risk-taking, in this context, with freedom and independence. As a rhetorical idiom it works as the moral opposite of interference and control. Yet, despite all the good intentions, the authors of the report cannot quite accept that the logic of risk is freedom. Invariably the affirmation of risk-taking is qualified by the presumption that this is an activity that users cannot entirely do for themselves, but which requires the support of service providers. 'With effective personalisation comes the need to manage risk for people to make decisions possible', states the report. Note the term 'manage risk for people'.

The report continues to clarify that it is the service provider that empowers risk-taking, rather than the user acting in accordance with his or her own inclination. It states that 'making risks clear and understood is crucial to empowering service users and carers, recognising people as "experts" in their own lives' (Department of Health, 2010, pp. 25–26). That risks are 'made clear' for users suggests that people are in fact regarded as anything but 'experts in their own lives'. In effect, this statement proposes a more nuanced and intelligent form of risk management, calling for 'managing risks to maximise people's choice and control over services', which implies a preparedness to allow for greater discretion in the provision of care (Department of Health, 2010, pp. 26). So the more positive orientation towards risk-taking is integral to the project attempting to introduce a more flexible and less intrusive managerial approach to adult care. However the principal objective of the policy is the adoption of a more targeted form of risk management, rather than a radically new approach to risk-taking.

However, even the call to adopt a more flexible (as opposed to a radically different) attitude towards risk-taking faces significant cultural and institutional obstacles. Despite the rhetorical acceptance of the right to take risks, risk is still regarded as a negative dimension of human experience. The College of Social Work's response to *Vision For Adult Care* boasted that 'we are good at assessing risk, explaining risk and working with people to minimise risk' (BASW, 2010). In this regard, risk minimisation is seen as synonymous with harm reduction.

The view that 'risk' is another term for 'harm' exists in an uneasy relationship with the recent call for greater toleration of risk. Official statements attempting to justify this new turn claim that 'reasonable risks' are necessary for the pursuit of an independent and autonomous existence. This approach was already emphasised by the Department of Health back in 2007, in a document that noted:

*Fear of supporting people to take reasonable risks in their daily lives can prevent them from doing the things that most people take for granted. What needs to be considered are the consequence of an action and the likelihood of any harm from it. By taking account of the benefits in terms of independence, well-being and choice, it should be possible for a person to have a support plan which enables them to manage identified risks and to live their lives in ways which best suit them.* (Department of Health, 2007, pp. 1–2)

Although this statement recognises the important benefits of risk-taking, its focus is the instigation of a new form of risk management. Risk-taking is still represented as an activity that requires professional monitoring. The report calls for ‘shifting the balance away from risk-aversion towards supported decision-making’. Just how much more freedom is gained by care users through ‘supported decision-making’ is far from evident and is likely to vary from one case to the next. In any case, ‘balancing service user risk-taking, rights, autonomy and empowerment with issues of protection’ in ‘a context of limited resources, increasing public scrutiny and fear of professional litigation is complicated’ (Mitchell and Glendinning, 2008), pp. 299).

The right to take risks is in reality a rhetorical idiom that connotes the promise of a degree of self-determination over decision-making. It is not a formal or legal right and is rarely even defined in official documents that promote it. Our analysis of its usage suggests that it is deployed as a form of qualification on the pursuit of inflexible risk management. A briefing produced by the Social Care Institute for Excellence states:

*Before the support plan can be put into place it must be approved by the council. Risk identification and management is an important function at this stage. The intention is to manage risk, not to eliminate it entirely and there should be recognition of the individual’s right to take risks in the same way as other people do in their own lives. The support plan should also state how it will meet the overarching outcome of keeping the individual healthy and safe and contributing to their wellbeing.* (SCIE, 2009)

Here the right to take risks is connected to the normal freedom that ‘other people’ possess to run their lives. In this context, the right to take risks is the corollary of diminishing the (often institutional) control that carers exercise over the user. The advocacy of risk-taking has as its focus the objective of altering the behaviour of institutions and carers. However, in so far as there is an identifiable institutional problem, it is that of providing flexible and context specific form of care.

One of the unexplored issues that has a decisive impact on the risk culture of social care is the capacity of carers to respond flexibly to the needs of users. Providers of care have to respond to a variety of conflicting pressures, including constraints on resources, institutional pressure, and concerns about the attitudes of family members and the community. In such circumstances, these conflicting concerns can compromise the potential for flexibility. The current defensive regime of social care prevents professionals from adopting a more user-centred approach, which is why we need to shift the ‘focus towards defensible rather than defensive practice’ (Ray, Bernard and Phillips, 2009, pp. 48). One important component of such a defensible practice is taking decisions on the basis of a discussion and negotiation with the service users affected.

## Reflections on risk and contemporary culture

A precondition for adopting a more balanced orientation towards user freedom and autonomy is to clarify why risk has become problematised and why the use of a risk discourse may well be unhelpful for clarifying the issues at stake. It is widely agreed that 'risk is a central defining feature and area of concern in adult social care provision' (Mitchell and Glendinning, 2008, pp. 297). A variety of motives, from the imperative of providing greater efficiency to the development of a greater sense of user responsibility, have been identified with the pursuit of a risk agenda in this area (Kemshall, 2002; Ray, Bernard and Phillips, 2009). However, it is important to note that the policy agenda that has led to the rise of risk consciousness in adult care parallels the emergence of similar trends in society. The frequent calls for 'balance and proportionality' in dealing with risks expresses widespread concern with the disorienting and destabilising consequences of the stigmatisation of risk (Better Regulation Commission, 2006). The concept of risk should not be confused with uncertainty: both are very different concepts. Risk pertains to the making of calculations where information is available and assessment is made on the basis of probability, whereas uncertainty refers to circumstances where the absence of data makes it difficult to draw strong conclusions since probabilities are unknown. Historically science and knowledge helped to transform uncertainty into risk and allowed calculations to be made. The reason why risk and uncertainty are often confused today is because of a growing cultural pessimism towards calculating outcomes. According to conventional wisdom, there is no longer such a phenomenon as a 'good risk'. Risk has transformed from a concept that is about the probability of outcome into a danger that must be avoided at all costs.

As I argue elsewhere, pessimism towards the ability to calculate outcomes leads to a form of worst case thinking, which in turn leads to the reluctance to tolerate risks (Furedi, 2009). This represents a shift from *probabilistic* to *possibilistic* thinking about risk, which imagines that anything can happen and is thus drawn towards acting in accordance with worst case scenarios. That is why 'good practice' is so often equated with risk minimisation. The aversion towards risk by organisations and practitioners involved in social care can thus be interpreted as a specific manifestation of a culture-wide reluctance to tolerate uncertainty.

It is widely recognised that the institutionalisation of the tendency not to tolerate risk has had a regressive impact on the provision of social services. It has led to micro-management and the blossoming of rules. Numerous home carers told me that it sometimes seems that they spend more time writing notes than looking after their clients. It is the recognition that risk management has become too bureaucratic and inflexible that has encouraged calls for a 'redefinition of society's approach to risk management, to recognise that, within the right circumstances, risk can be beneficial, balancing necessary levels of protection with preserving reasonable levels of choice and control' (Department of Health, 2007, pp.1).

However, the call to tolerate more risks is continually challenged by the institutional imperative towards minimising uncertainty. It is important to observe that calls for greater tolerance of risk are often followed by the recognition that not too much can be left to chance. Hence despite its intention, the reorientation towards personalisation of adult care does not represent a significant diminishing of

regulation – it merely means a change in form. So a report devoted to the promotion of the personalisation agenda is forced to reconcile this with the creation of new forms of process. After noting the benefits of tolerating more risks, the report notes:

*Even when good approaches are used and the correct processes followed, the reality is that, if something goes wrong, sometimes people may not want to accept responsibility and will look for someone else to blame. It is therefore vital to keep accurate records of discussions that take place about areas of choice. Such documentation will be critical in order to protect the person in making their choices, as well as the position of the local authority, PCT [Primary Care Trust] or private provider of care in the event of any complaints or litigation. They are also valuable in giving a structure to the discussion about choices and their consequences. (Department of Health, 2007, pp.2).*

Clearly the assumption that organisations need to be insulated from blame ‘if something goes wrong’ influences institutional thinking, leading to a one-dimensional reliance on procedure and paper trails. The real problem with this emphasis on record keeping as guarantor of integrity is that it tends to formalise relationships within adult care. When carers are expected to act defensively to ‘protect’ themselves and the local authority, they may not always be in a position to interact with users in accordance with the dictates of their professional judgements. The formalisation of care deprives relationships of a genuine interaction with users. Indeed it turns a relationship into a formal transaction. In some circumstances the rule book can be experienced as an obstacle to the provision of the kind of care that users wish to receive and carers would like to provide. To some extent carers will always face the dilemma of reconciling their duty of care with user aspiration for autonomy – a point that is recognised by the Social Care Institute for Excellence:

*The assessment of risk has often raised difficult questions for practitioners balancing empowerment with duty of care. The rights of adults to live independent lives and to take the risks they choose need to be weighed carefully against the likelihood of significant harm arising from the situation in question. (SCIE, 2010)*

However, this tension between empowerment and duty of care remains unresolved by policy.

Carers are continually confronted with the tension between demands for flexible and personal assistance and the schedules and rules that govern their work. ‘On the one hand, staff members have to provide compassionate care and, on the other, they have to cope with the pressures of the institution’, notes one study of staff interpretations of their experience in nursing homes (Persson and Wasterfors, 2009, pp. 2). Such conflicts are particularly striking in an institutional setting:

*As staff members explain their inability to let the elderly residents decide for themselves, they invoke organisational limitations to account for their behaviour. By blaming the schedule, staff members appear to be powerless to let residents decide when to have a shower (and when not to). (Persson and Wasterfors, 2009, pp. 4).*

But even home visitors indicate that they often find that their capacity to provide real care is undermined by the constraints of time and the rules that govern their work (Age Concern home visitors, personal communications, 2010). 'They have ripped out the heart out of caring,' one residential care worker told me.

## **The need for a new discourse of risk in adult care**

Risk has been transformed by the cultural script that has been communicated over the past three decades. Now risk is not simply something to be managed, but is constitutive of individual identity, where to be 'at risk' represents a clear statement about a person. As one review of the relationship between risk and older people observed: 'whether we are conscious of it or not, social work practice with older people often involves defining and constructing them as being "at risk" and evidence by conceptions such as "frailty" or "dependence"' (Ray, Bernard and Phillips, 2009, pp. 35). In fact it is the dominant cultural script, rather than simply social work practice, that promotes the tendency for old age to be equated with being at risk. The identity of being 'at risk' is frequently linked to its companion term, 'vulnerability'. Once users of care are assessed through the prism of risk it becomes difficult to perceive them as individuals with a capacity for agency. According to one account, a risk-dominated approach to assessment will 'reduce the potential for assessments and interventions to be grounded in strengths-based approaches, or approaches that take properly into account the perspectives, expertise and aspirations of older people' (Ray, Bernard and Phillips, 2009, pp. 42–43.).

The *possibilistic* orientation to risk signals a fundamental redefinition of the relationship between people and risk. According to this paradigm, people do not so much take risks as suffer their consequences. They are represented as 'the vulnerable'. As the use of the definite article 'the' indicates, vulnerability is not a passing phase – rather, it is the defining feature of an individual's identity. So the term 'vulnerable adult' is not simply a form of official designation but a statement of identity. The Safeguarding Vulnerable Groups Act 2006 has an expansive definition of who qualifies for the identity of a vulnerable adult. The list includes literally everyone who comes into regular contact with social and health care, and criminal justice services (The Safeguarding Vulnerable Groups Act 2006). The mere association with the usage of care services automatically endows a person with the status of vulnerable adult.

Earlier this year there has been a call to replace the concept of 'vulnerable adult' with that of 'adult at risk'. According to the Social Care Institute for Excellence:

*Adult at risk are people over 18 years of age who are or may be in need of community care services by reason of mental health, age or illness, and who are or may be unable to take care of themselves, or protect themselves against significant harm or exploitation. The term replaces 'vulnerable adults'. (SCIE, 2011).*

It is far from evident why the label 'adult at risk' represents an advance over the previous designation. On the contrary, the concept invokes an interpretation of human agency that represents the very antithesis of the kind of choice and risk-taking advocated by policy-makers.

The concept of **being at risk** encapsulates an outlook that is dramatically different from the classical notion of **taking a risk**. The formulation of taking a risk contains the assumption that individuals can both exercise choice and choose to explore and experiment. Taking a risk has as its premise active subjects whose actions have the potential to realise positive outcomes and to alter their circumstances. In contrast, the concept 'being at risk' reverses the previous relationship between human beings and experience, assigning to the person a passive and dependent role. To be at risk is no longer about what you do – it is about who you are. It is an acknowledgement of powerlessness, at least in relation to that risk. Increasingly, someone defined as being at risk is seen to exist in a permanent condition of vulnerability. This trend acquires its most striking expression through the widely-used expression the 'at-risk child', and it is not surprising that practices associated with child protection have been internalised by policy dealing with adult care. In some reports the Every Child Matters reforms of children's services are put forward as compatible with the delivery of adult care (see for example Hudson, Dearey and Glendinning, 2005, pp.1, 8 and 18).

There is some pressure from advocacy groups to adopt a more nuanced approach towards risk-taking as part of a normalisation strategy towards users of care. And although this pressure has succeeded in influencing deliberations over policy-making, it is far from clear whether it has had a significant impact over the risk culture in adult care. It is likely that the negative risk narrative that prevails in adult care has had an impact on users of services. Researchers have noted that 'increased managerialism' in adult care has encouraged the tendency towards risk aversion (see for example Ray, Bernard and Phillips, 2009, pp. 52). However the impact of an ethos of risk aversion on adult care has not been systematically analysed. My own discussions with adult users of care indicate that attitudes towards risk-taking may be far more variable and more restrained than suggested by policy-makers.

Carers frequently noted that younger adults sought opportunities for leading a 'normal' life. Some attempted to gain significant control over their everyday routines and aspired to the role of autonomous decision-maker. However, while many younger adults are interested in gaining more independence, I was struck by the absence of an appetite for risk among older people. Certainly my very preliminary soundings indicate that the idea of being 'at risk' has been thoroughly internalised and many are choosing options, such as living in a residential home, precisely because they are less exposed to uncertainty. Users of care want consistency of service and reliable support. They want to be taken seriously as people but not necessarily as risk-takers.

## **The problem of trust**

At its best, risk-taking in adult care is 'based on a view of the service user as an active citizen with rights and responsibilities and it values the individual's own expertise, rather than seeing professionals as the only experts' (Stalker, 2003, pp. 223). From this perspective, risk-taking is identified with the pursuit of a self-influenced lifestyle that allows service users to set their own agendas. Although this ideal is recognised in the social work literature, in practice there are very severe limits towards tolerating risk-taking among service users. As one review of the

literature concluded, 'in practice...it is usually social workers who make the final decision about whether or not certain risk is acceptable' (Stalker, 2003, pp. 224). It is important to understand that limits on the risk-taking activities of users of care are not simply the consequences of a defensive professional culture. Despite the shift towards personalisation, the assumption that the professional knows best continues to dominate adult care. The rhetoric of individual users being the experts tends to be just rhetoric. 'We go through the motions – but that's as far as it goes,' one social worker told me (interview, 2011). This trend is far more pronounced in the treatment of older people. In a world where being old receives little cultural affirmation, it is not surprising that the elderly are regarded as anything but experts. Research has consistently shown that there is a 'widely held perception that people over 50 are likely to be "written off"' (Abrams, Eilola, and Swift, 2009, pp. 6). One former local authority manager involved in adult care takes the view that the 'experience and outlook of older people is constantly denigrated in the wider world', so it is not surprising that such prejudices also influence the ethos of care (interview, 2011). Research has drawn attention to the use of 'infantilising language' by homecare workers when communicating with homecare users (Leece and Peace, 2010, pp.1858).

Observing from the outside, it appears that the relative lack of trust in service users' capacity to make sound decisions is not unconnected to the institutionalisation of mistrust towards the exercise of professional judgment. The prevailing ethos in the organisation of care leaves little room for carers to exercise discretion. Carers frequently told me that they often feel obliged to act according to the rules rather than their professional intuition. In such circumstances, the lack of validation for professional judgement fosters a climate where trust – including users' trust of carers – may be undermined.

Many users of care find that their needs may contradict the concerns of their family members and carers. Consequently users of care, especially older people, feel insecure about what to expect from others and are frequently hesitant about trusting people with whom they come into contact. There is evidence that some 'did not trust care workers or friends but did trust neighbours, some acquaintances and even strangers' (Dixon, Manthorpe, Biggs, Mowlam, Tenant, Tinker and McCreadie, 2010, pp. 410). One local authority executive told me that she is constantly surprised by the number of serious disputes between care users and family members that require her attention. She told me of a number of cases where family members have sought to prevent their elder relatives from accessing their bank accounts. Research has identified a 'generation divide', whereby the resistance to having to pay for parents' care costs strengthens as people get older (Ipsos MORI, 2011, pp. 14). Not surprisingly, users of care sometimes feel that their best interests are not served by their relatives. In such circumstances, research has noted that 'older people sometimes engaged covertly in risky actions, unbeknown to their informal or paid carers' (Mitchell and Glendenning, 2008), pp. 304). It is worth noting that such covert behaviour tends to be an expression of those who feel that they lack the power to assert their claims openly.

The perceptions of users of care towards risk are linked to their sense of security and trust towards carers and family members. Yet by all accounts, the relationship between these groups is not always harmonious and often appears to contain a

conflict of interest. This is an issue that touches on generational conflict and the tension between user needs and the maintenance of institutional safeguards. Since so many of the issues associated with this conflict remain implicit, it is essential that research aims to unravel its different dimensions. Such conflicts frequently focus on the distribution of family financial resources. But they also relate to pressures of time and disputes about responsibility for caring (see the discussion in Ipsos MORI, 2011, pp14–15).

There are different ways of interpreting the question of trust. However in the context of adult care, it is most useful to interpret it as a statement about existential security. Trust and feeling of security provides the foundation for feeling empowered to engage with uncertainty and for taking risks that are appropriate to circumstances. Users obviously require their carers to be professionals whose work adheres to the highest standards. However, adult users also want a form of care that is not simply a professional transaction but also a personal relationship. When older users talk about their carers, they appear as interested in their personal attributes as their professional competence. Small gestures, such as a smile, asking carers about their views about routine issues, or remembering how they take their tea, make all the difference. In conversations, users talk at great length about individual carers and regard them as people who are important to their lives. Such relationships help to strengthen users' sense of security.

One of the major challenges facing the institution of adult care is to learn to accept the risk of tolerating the cultivation of a more user-centred relationship. It is far easier to manage the risks associated with a formal transaction than to tolerate a more personal form of care. Paradoxically, in a world where personalisation has become the driver of policy, very little is said about this matter. It is important not to confuse a personalised care plan with the cultivation of a more personal/informal form of care relationship. Too often a personalised care plan turns out to be a bureaucratic exercise in box-ticking. One manager has described it as a mechanism for establishing the 'parameters of care' (interview, 2011).

What's required is not less intrusive risk management but a genuine willingness to offer a more informal and flexible care relationship. The personalisation agenda, with its emphasis on promoting independence and choice, has the potential for meeting the need for a more informal care relationship. But whether that potential is realised depends on providing professional carers with greater scope to exercise discretion and judgment. Without adopting such an orientation, the pluralisation of adult care provision can lead to the reproduction of the prevailing impersonal and risk-averse regime, albeit in a more segmented and chaotic form.

## Conclusions

Our discussion of *societal attitudes* towards risk-taking in adult care is constrained by the relative weakness of the quality of the available evidence. Despite the numerous claims that the 'public wants this', it is far from evident whether there are clearly identifiable attitudes towards the question of risk-taking in adult care. Public opinion research suggests that on most issues, people's opinions are far from stable. As Zaller notes: 'citizens do not typically carry around in their heads fixed attitudes on

every issue on which a pollster may happen to inquire' (Zaller, 2006, pp. 1). Studies of public opinion polling suggest that respondents construct 'opinion statements' on the spur of the moment. As Taylor and Fiske (1978) note, people's responses are guided by concerns that are most salient to their lives at the 'top of the head'. This gap in our understanding of public opinion towards adult care is emphasised by a recent report by Ipsos MORI for the Commission on the Funding of Care and Support, which notes:

*This review shows that while public opinion research on funding of social care has been covered in some breadth, few aspects have been explored in much depth. Much of the research is based around top of mind polling which gives a representative view of what the public thinks, but often relies on a handful of questions that do not explore people's views in much detail. There is some qualitative work that does cover perceptions in more depth, but this is far from comprehensive in coverage. (Ipsos MORI, 2011, pp. 36)*

The Ipsos MORI report has as its focus public opinion regarding the funding of social care: an area that has been far more investigated than any other dimension of this issue. Yet even on this subject it is difficult to gain a measure of public attitudes. As the report notes, 'there is a low level of awareness about social care generally, and discussion about the future funding of long-term care is outside most people's normal terms of reference' (Ipsos MORI, 2011, pp. 1). From our review of the available literature, it appears that the question of risk-taking in adult care is even more remote from people's routine terms of reference. At the very least we need more research on the attitudes that different types of users of adult care have towards risk-taking.

The limited evidence available to us suggests that the current focus on establishing a more robust risk-taking culture is not so much a response to user demand but a result of deliberation by policy-makers. That the impulse behind this agenda is policy-driven does not invalidate the claims made on its behalf. There is little doubt that adult care requires a more sensitive, flexible and contextual approach. However, it is important that the current personalisation agenda is not equated with a more flexible and risk-positive approach. By all accounts, this agenda aims to modify the way that risk is managed, rather than to provide more opportunities for users to assume greater control over their lives.

The aspiration of providing greater opportunities for users of care to take decisions about matters that affect their lives is a worthy one. But the realisation of such aspirations requires more than just a change in rules. The precondition for the emergence of a more flexible system of adult care is a change in ethos. In particular it requires a greater tolerance towards uncertainty and uncertain outcomes. It is also necessary to provide care professionals with greater freedom to exercise their judgement. It is inconceivable that a robust risk-taking culture can be established in adult care without providing professionals with greater freedom to exercise discretion about how they respond to the needs of individual users. A serious conversation between policy-makers and carers is essential in order to work out an approach that reconciles flexibility and quality of care with a joint assumption of responsibility. That requires policy-makers to listen and act on proposals suggested by carers. For their

part, carers need to work out how the service they provide can be offered in a more flexible and context-specific manner.

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