

IMPROVING DECISION- MAKING IN THE CARE OF OLDER PEOPLE EXPLORING THE DECISION ECOLOGY

RSA Action and Research Centre

This report explores the issues of risk and trust in relation to the care of older people, focusing in particular on decision-making.

In the next forty years the proportion of the population in retirement is estimated to rise significantly. This major demographic change makes it imperative to review the position of older people both as receivers and as givers of care and support.

The report includes:

- an examination of the nature of decision-making;
- an exploration of the 'decision ecology' – the multi-factored contextual backdrop to decisions about risk and trust in an ageing society;
- a discussion of factors that influence, improve and impede caring decisions taken by a range of actors;
- a consideration of the role of narratives in improving decisions for, by and about older people and their care;
- an appraisal of risk management and trust development strategies;
- an investigation of responsibility in decision-making.

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EXECUTIVE SUMMARY

In the next 40 years the proportion of the population in retirement is estimated to rise significantly, and this makes it imperative to review the position of older people, both as receivers and as givers of care and support.

This report concentrates on the question of how to improve decision-making in the care of older people – of formal and informal carers – in order to promote a more effective and rewarding environment for older people and those who care for them.

We conducted a literature review and used an expansive method, taking into consideration non-academic and anecdotal evidence in addition to academic literature. Although we chose to focus our inquiry by using decision-making as the lens through which to examine notions of risk and trust in an ageing society, it is important to accept that the traditional view that decisions are made on the basis of logic and rationale is out-dated. Rather, a range of factors influence how we make decisions, including the role of habit, the desire for cognitive consistency, the influence of social norms, gut instinct and the need to feel like we are ‘doing the right thing’.

This ‘decision ecology’ is the multi-factored contextual backdrop to decisions about risk and trust in an ageing society, and there are many actors in the decision ecology, including older people, their families, formal carers, neighbours, friends and the community at large, all of whom face decisions which are affected by differing understandings of risk and varying degrees of trust.

Caring decisions are complex, and affected by a range of factors such as mood and perceptions of security, with people in various roles seeing situations differently and bringing different needs and interests to the decision-making process. Many factors may influence players involved in caring decisions, including negative stereotypes and visual images of older people, cultural perceptions of those in need (a hardening of attitudes), attitudes to risk (and in particular, our tendency to ignore risks if we believe something will benefit us), mood (negative mood is associated with risk avoidance) and gender (with women more likely to see risks as problematic).

There is evidence that high-trust relationships are a major factor in making good decisions, and we have reason to believe that acknowledging

different points of view helps build trust. Factors that undermine trust reduce the likelihood of good decision-making, for example, high staff turnover, perceived professional incompetence and lack of trust between the different actors involved in care.

Helping older people to frame and share their own personal narratives is one way of building such trust, and professionals have the opportunity to assist older people in structuring and telling their own stories as a means to gain and maintain autonomy and to make decisions with confidence. Narratives can act as a vehicle to understanding the processes by which individuals and organisations structure their understandings of risk, develop their strategies for engendering trust and make positive decisions about their lives.

Excessive risk aversion in formal care settings and within families can damage older people's wellbeing, but the rise of a 'culture of blame' in society as a whole has heightened the need for practitioners to protect their own interests. However, when older people are a group to be managed under the same set of provisions, avoiding the 'risk' of being held accountable for quotidian hazards may be given too much weight at the expense of proper regard for the risk of compromising a particular person's integrity and autonomy. This may lead to a breakdown in trust and poor decision-making.

Professionals and the wider public must recognise that *risk elimination* is a myth – the wellbeing of older people requires positive risk-taking, and things sometimes go wrong without it being anyone's fault. We agree with a range of commentators who are calling for a major shift in approach, away from extreme risk aversion to one in which *positive risk-taking* is embraced as a means of enabling independence, confidence and self-worth.

There is contention as to who should take responsibility for decisions about older people and their care. In our view there has to be shared responsibility, with a distribution that takes account of the different players' capacities and relevant expertise in respect of the specific decisions to be made. Shared partnership must be based on the recognition that things inevitably go wrong sometimes, and professional carers, informal carers or older people themselves shouldn't be burdened with all the responsibility.

There is a range of resources that can help take this forward in practice, including models such as double-loop decision-making (see pp. 48–9), the principles and guidelines associated with the Mental Capacity Act and the person-centred partnership approaches informing the care of people with dementia, learning disabilities and mental illness.

Rethinking the decision ecology means connecting a myriad of complex issues from a variety of disciplines and spheres. The challenge is that the issues are deep, broad and interconnected. Facing up to them means thinking not merely of the cognitive 'fit' between older people and the decisions we need them to take about their care, but also about the ethical and political 'fit' between the kinds of personal and psychological qualities that seem to matter – attitudes to risk, willingness to trust and daring to be kind. It is essential that we cultivate respect for the differing knowledge and understandings of all the actors in the decision ecology and that we appreciate they will all have positive contributions as well as shortcomings. A mature understanding of this complexity is what is needed because a necessary precondition for effective decision-making is to build mutual trust between actors from different spheres.

It is also important to maintain awareness of older people as major contributors within the decision ecology – their experience and ability to make decisions must be respected, and we must strive to avoid positioning them primarily as 'passive' recipients of care.

Further exploration of the 'decision ecology' might give rise to a deeper understanding of the ways in which positive societal contributions to and from older people can be strengthened – how people and communities can be encouraged to become more kind – and how the formal social care system can better accommodate and use informal and semi-formal caring relationships.

1 OVERVIEW

The scale of demographic change in the UK and the challenges it brings means it is vital that we consider the role of older people as both receivers and givers of care and support.

Recalibrating for an ageing society

Our society is ageing. Between 2012 and 2050, the proportion of the population in retirement will rise from about 17 per cent to 24 per cent, and the number of people over the age of 80 will almost triple, to eight million. Economic and social challenges will undoubtedly follow from this change. It has been estimated that the numbers of older people needing access to social care will double in the next 30 years, and this will include some of the 1.4 million people expected to have dementia (CSJ, 2011). Older people receive a substantial proportion of the unpaid care and support (estimated to be worth £87 billion every year) given by six million informal carers in the UK (CSJ, 2011). However, the contribution made by older people as providers of care is often overlooked – nearly a third of the people providing unpaid care are over the age of 60 (Ross *et al.*, 2008), and it has been suggested that they will play a major role in providing the additional care that is needed (Pickard, 2004). Older people also provide considerable amounts of support to younger generations, including care for adult children with disabilities and general support to adult children such as with childcare.

Demographic change on such a scale makes it imperative to review the position of older people as both receivers and givers of care and support. We need to consider how positive societal contributions to and from older people can be strengthened, and how the social care system can better accommodate semi-formal and informal relationships in which high levels of understanding and kindness are embedded. Volunteering and a 'Big Society' approach to helping older people maintain independence are familiar themes in the visioning reports and White Papers emerging from the Department of Health and other government departments.¹ According to a recent strategic paper on volunteering, 'Our vision is of a society in which social action and reciprocity are the norm and where volunteering is encouraged, promoted and supported because it has the power to enhance quality, reduce inequality or improve outcomes in health, public health and social care' (DH, 2011).

p. 9). There is also an agenda to empower older people by giving them greater choice and control over the kind of support they receive, expressed, for example, in policies of self-directed support and personal budgets.

Critiques of initiatives based on notions such as ‘community care’ or the ‘Big Society’ have exposed the role of rhetoric in masking cost-cutting measures as successive governments have attempted to limit the spiralling costs of health and social care, and the budget for care for older people is likely to remain under pressure in the foreseeable future. Our task is to consider how older people, state services, family and community can work together to provide good quality care for those who need it.

Our review of the evidence has, therefore, been underpinned by the following:

- 1 What would help make people more confident to make better decisions about caring for and supporting each other?
- 2 What helps or sustains people in local communities who ‘dare to be kind’?
- 3 How can society’s capacity to support an ageing society, and to deal with related risks, be strengthened (including why things go wrong and what helps make them go right)?
- 4 How do formal social care structures interact with informal and semi-formal spheres? What works and what needs to be changed?
- 5 What can formal social care practice and regulation learn from how risk and trust operate in informal and semi-formal spheres?

Grappling with risk and trust: the centrality of decisions

The extent to which this dual vision of a more autonomous older population and a more caring society can be realised will depend on how effectively risk can be managed and trust cultivated in formal, semi-formal and informal relationships. The vulnerability of older people raises especially difficult social and psychological challenges in managing risk for users and providers of care. Effective decision-making requires confidence in one’s judgements, even where the stakes are high and risk cannot be eliminated, and it is not always easy to be confident. For example, a volunteer may need to balance the risk of cooking food for an elderly neighbour with the risk of not doing so; a family carer may have to weigh up the risk of a serious fall against the benefits of allowing an older person to continue to manage their own washing and dressing in privacy.

We did not seek to answer directly the five questions set out above, but used them as a platform from which to review available evidence. We focused on personal decision-making as a central theme of our enquiry for three related reasons:

- The social, demographic and policy context outlined above has generated complex practical, ethical and regulatory issues relating to personal autonomy and accountability, and the front line for many of those issues will be the basis on which decisions are made and justified with confidence.
- Creating such confidence means ensuring there is a ‘fit’ between the kinds of decisions people are being asked to make, and their decision-making capacities.
- In the process of making sense of this ‘fit’ we need to recognise that our understanding of what decision-making entails has changed significantly, such that it no longer makes sense to think of decisions as if they arose

from personal calculation, and ‘confidence’ can only be understood in a wider social and policy context that we call the ‘decision ecology’.

One issue hampering efforts to promote greater autonomy for older people and to encourage more involvement of the wider community is society’s problematic relationship with risk and trust. The proportion of British people who say they generally trust others dropped from 60 per cent in 1959 to 30 per cent in 2005 and has since declined further (Green *et al.*, 2011). Our understanding and perception of risk is similarly problematic. In his scoping paper for the Joseph Rowntree Foundation, Furedi (2011, p. 12) noted, ‘Risk has transformed from a concept that is about the probability of an outcome into a danger that must be avoided at all costs.’ Similarly, Alaszewski *et al.* (2004, quoted in Mitchell and Glendinning, 2007) argued that ‘risk’ has become heavily laden with negative connotations, resulting in frequent calls for the state to step in and provide appropriate (and sometimes inappropriate) safeguards.

In a climate where it is believed that if something goes wrong it must be someone’s fault, there is a serious risk of ‘defensive’ intervention, where individuals avoid getting involved with caring for friends and neighbours, and where those with formal caring responsibilities do what will minimise the chances of themselves being criticised or reprimanded. This is certainly not in the best interests of older people. Given this, how can we best ensure that there is a significant allocation of caring responsibilities to service users and those informal carers, alongside more formal care service relationships? Glasby (2011) is one of many to argue for a change in top-down risk management, proposing instead that risk should be shared between the person who takes the risk and the system that is trying to support them, although this is a complex challenge.

The severity of a risk is a product of both ‘hazard’ and ‘harm’, that is, the likelihood of something going wrong and of the severity of the resulting consequences should it do so. While informal and semi-formal relationships may help to reduce hazard (Glasby, 2011), patterns of accountability at the statutory level mean that the ultimate responsibility for harm is a human rights issue, and typically rests in more formal relationships (Marchant, 2011). A major challenge is to ensure that formal attempts to reduce the harm resulting from risk do not undermine the informal and semi-formal relationships that may reduce hazard and increase the overall wellbeing of older people.

About this report

In this report we seek to build a deeper understanding of this challenge by enriching our grasp of what we have chosen to call the ‘decision ecology’ in an ageing society. We look at the interactions between different actors involved in making decisions about support for older people (formal, semi-formal, informal and older people themselves), consider their role in the decision-making and risk management processes, and explore the implications for each of these taking and allocating such decisions. Our aim is to expose underlying tensions and to begin to paint a picture of how decisions about providing care and support could and should be allocated to improve the wellbeing of older people, to make best use of the available support from informal and semi-formal relationships and to complement existing formal structures. In some ways this entire report is a wide-ranging attempt to make sense of what it might mean to care. It therefore seems

too limiting to define care too prescriptively at this point, but we do make a distinction between care as affection and kindness between human beings, and care as a form of institutional protection between individuals and the state. With this in mind, we tried to navigate the complex morphology of care. When we refer to care in the report, we refer to formal, semi-formal and informal care. At points in the report when we mean to refer to one or the other, we prefix the term care with 'formal', 'informal' or 'semi-formal'. Occasionally we use the term 'non-formal' to capture both informal and semi-formal care. The term 'care' itself refers to a large range of activities, from regular, intensive care (for example, helping an older person wash and dress everyday) to lighter, more flexible activities (for example, dropping in to see an older neighbour once a fortnight). We distinguish between different levels of care where necessary.

Our decision to view this challenge through the lens of personal decision-making rather than just from a policy or sociological viewpoint stems from our desire to get a deeper, more granular perspective on why different actors in the decision-making ecology behave in the way that they do. Drawing on our existing knowledge of neuroscience built up through the RSA's Social Brain programme, we aim to scrutinise the decisions made by different actors in the decision-making ecology and in doing so, breathe fresh air into the debate around risk, trust and an ageing society.

In practice, this has meant looking at the particular cognitive dispositions which affect people's capacity to make informed decisions as they get older, exploring the powerful role that narratives and story-telling can play in driving affective decision-making and examining the way in which people's consideration of risk changes as they age. This stands in contrast to more conventional research approaches based on a model of people as purely rational, utility-maximising beings.

Our approach, in common with much of the RSA's work, is based on the tenet that only by knowing ourselves better can we achieve long-lasting and substantial social change. We suggest that in order to close our 'social aspiration gap' – the gap between the world we aspire towards and the one we are creating through existing forms of behaviour and thinking – citizens need to be in aggregate more engaged, more resourceful and more pro-social (Taylor, 2007). Understanding why we make decisions in the way we do can enhance efforts to cultivate these capabilities, all of which are necessary for fostering a more caring citizenry.

Rather than attempt to offer a comprehensive investigation of the full range of issues and debates about risk, trust and an ageing society, this report is focused on the question of how to improve decision-making in the care of older people (of formal and informal carers), with a view to promoting a more effective and rewarding environment for older people and for those who care for them.

2 RESEARCH APPROACH AND PROCEDURE

This chapter explains the extent of the research and how it was carried out.

Approach

This is a review of academic and non-academic literature, anecdotal evidence and other material (for example, online testimonies from older people) relevant to risk, trust and relationships in an ageing society. Our review was informed by a 'realist' strategy for synthesising retrieved material. This allowed us to make sense of evidence that had an *explanatory* rather than a judgemental focus. Unlike conventional systematic reviews that exclude 'grey literature' and 'anecdotal' evidence from practitioners, the realist method is deliberately expansive and allows for different types of evidence to be considered in parallel. We also employed the grounded theory approach (Glaser and Strauss (1967, cited in Ryan, 2000) for developing theory and theoretical relationships from the body of evidence gathered. By employing these two approaches, the overall method had an exploratory and inductive focus, where the analysis started with an initial set of themes that could later become less important as newer interesting and relevant themes emerged from the data.

In undertaking the review, we:

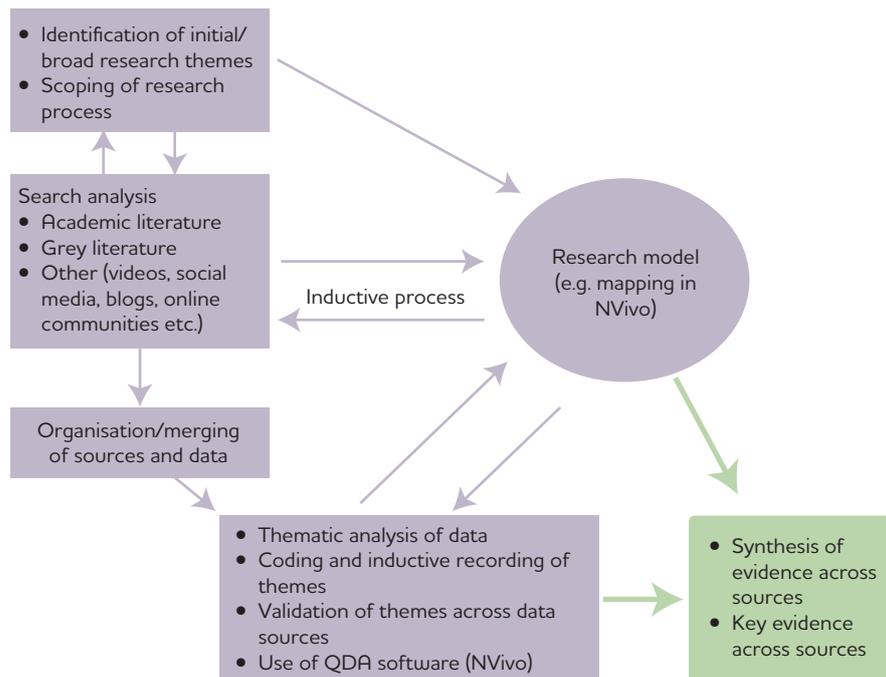
- searched seven electronic databases using an iterative search strategy described in more detail below;
- searched for non-academic literature through website searching and using professional contacts;
- searched for anecdotal evidence using professional knowledge of pertinent websites and search engines;
- applied a series of common-sense and predetermined exclusion criteria to the retrieved documents to ensure only relevant literature was included;
- extracted data from remaining material into a pro-forma spreadsheet;

- entered content into NVivo, a qualitative data analysis tool, to conduct thematic and content-based analysis to inform the review.

Research process model

A process model was developed to map the various stages of the research. The overall approach for the research was interactive and iterative; researchers involved had a number of opportunities to share and discuss their findings. The model is shown in Figure 1.

Figure 1: Research process model



Search strategy

An initial workshop was held in which the research team agreed on an initial set of themes from which a list of search terms was developed. These search terms were identified through a close reading of all existing Joseph Rowntree Foundation (JRF) publications sitting under the 'Risk, Trust and Relationships' work programme (Barr *et al.*, 2001; Beresford and Andrews, 2012; Berry, 2011; Brindle, 2008; Falkingham *et al.*, 2010; Faulkner, 2012; Furedi, 2011; Gandhi and Bowers, 2008; Glasby, 2011; Glendinning and Bell, 2008; Marchant, 2011; Mitchell *et al.*, 2012; Wiseman, 2011; Young *et al.*, 2006), existing RSA publications on relationships and trust and an initial examination of relevant non-academic literature (see, for example, Clifton, 2011a, 2011b; Ipsos MORI, 2005; Parker *et al.*, 2008). This process allowed researchers to develop a list of search terms that would be used to systematically search for relevant evidence in academic, non-academic and anecdotal sources.

Evidence refinement

The initial academic and non-academic literature search identified many thousands of documents that might be germane to the review. In order to sharpen the search results to include only the most appropriate documents, we undertook three stages of filtering. The first was a simple stage of assessing whether a document was at all relevant to the main theme of the research, 'risk, trust and relationships in an ageing society'. A majority of documents identified were excluded at this stage.

The second stage involved a close reading of remaining documents to decide whether they should be entered into a spreadsheet for analysis. Material was included or excluded according to one or more of three tests:

- Methodological sophistication, particularly the degree to which social influences on risk, trust and decisions were recognised and analysed.
- Practical relevance, particularly the extent to which the evidence lent itself to credible and creative practical proposals.
- Corroboration with different forms of evidence deemed to have quality on the first two criteria (for example, where anecdotal evidence appeared to support existing academic findings).

Those documents that satisfied all three criteria were given priority in the coding stage described below. At this stage 317 items of evidence were entered into the spreadsheet.

NVivo qualitative data analysis

Data were coded in order to develop themes and to uncover relationships between items of evidence. Theme codes were attached to documents using the qualitative data analysis software NVivo 9, and documents uploaded into the software. Where a piece of evidence within a document matched a theme, the relevant sentences or paragraphs were highlighted and coded.

While reading and coding the papers, the research team identified new themes. Emergent themes were discussed among the researchers before it was agreed whether to include them in the coding frame. Due to the volume of evidence, it was not possible to apply new codes to papers previously coded, so we must acknowledge this weakness in the technique.

The software recorded the number of times that each theme had been coded across all the documents. This provided a guide as to the prevalence of the various themes. Thematic analysis was used to identify whether more research was needed to find further supporting evidence to explain particular themes identified as vital to the overall research purpose.

Relationships between themes were also identified through individual insights from the researchers. A systems map that describes the important relationships between the various themes was developed through a synthesis of these findings (see Figure 2). This process of compiling the map was interactive and collaborative, and each researcher offered critical comments on the nature of the relationships based on their independent insights.

Finally, an analytic workshop was held in which we used the systems map to discuss how best to structure our findings and prepare our report. In the chapters that follow we present our new perspectives on decision-making, outline the complex ecology in which decisions about older people's care are made, examine caring decisions in more detail, consider the role of narrative in making sense of the decision ecology, look at the complexities surrounding

risk and trust, ask questions about who has responsibility in a society that is ageing, and finally, consider the policy and practice implications arising from the review.

3 NEW KINDS OF DECISIONS

What exactly is involved in making the decisions that matter in an ageing society?

Nature of decision-making

When we think of ‘decisions’, we tend to imagine an individual consciously weighing up evidence rationally, and reaching a logical conclusion about a singularly correct course of action. In reality, most decision-making is not like that at all, but the traditional model of rational decision-making continues to prevail (Sen, 1977). In this chapter we seek to shift that emphasis by looking more deeply at what exactly is involved in the decisions that matter in an ageing society, including the myriad contextual, social, ethical, habitual and unconscious factors that shape our decisions, and also inform second-order decision-making, that is, our decisions about the basis on which decisions should be made.

The analytical foundations of rational decision-making have been called into question, and a new perspective is emerging in which more compelling factors that influence decisions are identified, including, *inter alia*, the role of habit, the desire for cognitive consistency, the influence of social norms and the need to feel like we are ‘doing the right thing’ (Rowson, 2011). Also important are biases such as the ‘endowment effect’, which explains people’s peculiar aversion to loss, our significant discounting of the future relative to the present, and the fact that we place more importance on relative rather than absolute values. The latter is substantiated in experiments showing that people would prefer a smaller income that was high relative to peers to a higher income in absolute terms that was low relative to peers (Haidt, 2007).

These factors are now the subject of a growing body of research evidence demonstrating the human tendency to be what Dan Ariely (2008) calls ‘predictably irrational’ and the wider range of non-rational influences on behaviour (see, for example, Dolan *et al.*, 2010). When considering what confident decision-making in an ageing society might comprise, we need to be aware that conscious rationality is the exception rather than the rule, and should not necessarily be expected as normal behaviour. In this respect it is

worth noting that one of the main practical pieces of advice stemming from the bestselling book *Nudge* is: 'expect error' (Thaler and Sunstein, 2008).²

Choice

Dowding (1992, cited in Arksey and Glendinning, 2007) proposed that for genuine choice to be possible people needed to have access to accurate, up-to-date information and at least two positive options (having options to choose from is widely considered to be fundamentally positive). A standard assumption in economic theory is that if someone has a choice, they are more likely to satisfy their preferences, and the chances of needs being met increase as the number of available alternatives increase. Dowding's (1992, cited in Arksey and Glendinning, 2007) model of extending choice through increasing the number of alternatives in a choice set is potentially applicable to our context, given the heterogeneity of carers, and the interdependence and potential for conflict that is inherent in the carer–care recipient dyad. In principle, the greater the diversity of provision, the greater the chances of carers and people receiving care to obtain help tailored to both their individual and joint priorities and preferences (Arksey and Glendinning, 2007, pp. 24–5).

However, this classic assumption that more choice alternatives lead to better outcomes has been rejected by some commentators, and we suggest approaching it with caution. For example, Barry Schwartz argues that too much choice could be detrimental to wellbeing, being burdensome, a source of confusion and an additional responsibility (Schwartz, 2004). Furthermore, we suggest considering the possibility that having access to many options, none of which are able to meet a person's needs, is potentially more stress-inducing than having only one unsatisfactory option. It may also be the case that Dowding's model is more useful in understanding goods markets than applied to the context of social care for older people.

The issue of choice more generally appeared in a range of settings in the literature reviewed. For instance, Arksey and Glendinning (2007) drew attention to the choices facing informal care-givers once they were committed to caring. Such choices might include whether to request, accept or reject support from social services, whether to admit the care-recipient to respite or residential care, and the choice of whether and how to combine paid work with care-giving. Certain policy initiatives set out to increase choice for the service user, but do not explore increasing choice for informal carers (Arksey and Glendinning, 2007, pp. 3–7). A systematic review conducted by Arksey and Glendinning (2007, p. 15) revealed a similar bias, suggesting that more consideration of the choices facing informal carers is urgently needed.

We assert that choice is not an individualised activity, but is rather one that takes place in a wider social arena. There are two sets of influencing factors, both of which can limit carers' opportunities to exercise choice. The first is the nature of the relationship within which care is given and received, which is often based on kinship ties and characterised by (the expectation of) a history of reciprocity, closeness, obligation and respect for the other person's preferences. The second set comprises wider organisational factors, in particular eligibility criteria, the limited availability of services, the lack of information, financial charges and the approach taken by professionals.

Discussion

It is all too common to take for granted the traditional assumption that decisions are made consciously and rationally, and that choice is an individual activity and inherently advantageous. We are convinced of the evidence that decision-making processes are in fact not rational, but rather are heavily influenced by both affective and social factors. Any consideration of how to foster confident decision-making in an ageing society must take this into account. Similarly, it is vital that we remain open to the possibility that too much choice, combined with the lack of support in forming strategies for choosing, can in itself be a source of stress for older people and those associated with their care. It is with these analytic insights in mind that we approach this review. In the following chapter we explore the context in which decisions facing older people, their carers and the wider community are made.

4 THE DECISION ECOLOGY

This chapter identifies and explores 11 broad topic areas that illustrate key features of the contextual backdrop to decision-making processes.

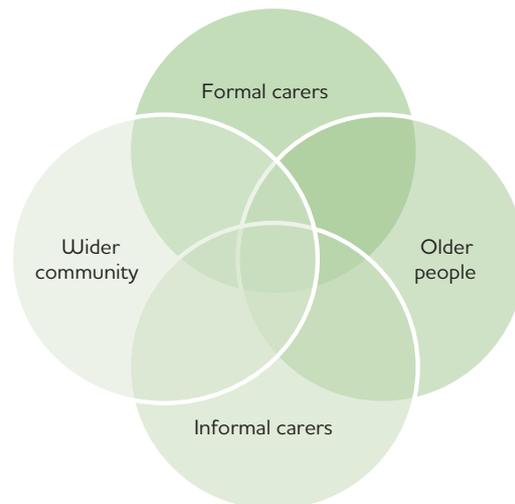
Introduction

The context in which decisions about risk and trust in an ageing society are made is intricate and involves a range of actors including older people, formal and informal carers and the wider community (neighbours, family and friends). We have chosen to describe this multi-factored contextual backdrop as the *decision ecology*, and our analysis of the evidence led us to identify three types of decision that characterise it:

- the decisions that older people make about their own care (including but not limited to how to manage risks they are taking);
- decisions made by or in collaboration with formal, informal and semi-formal carers about how care should be received (for example, what level of independence to support);
- decisions made by individuals outside of the immediate formal care infrastructure about whether or not to provide care and/or be kind to older people.

The roles that individuals play loosely fall into four categories: formal carers, older people, informal carers and the wider community (which includes aspects of semi-formal relationships and support, for instance, from church groups and charities) (see Figure 3). These roles are not bounded, with actors sometimes holding multiple identities and roles changing over time (Clifton, 2011a; Human Resources and Skills Development Canada, 2005). Decisions made by each of these actors affect each other – examples include the impact that risk management decisions by a formal carer have on limiting the independence of an older person. However, others include the effect that an older person's decisions could have on the health of their informal carer (Glendinning *et al.*, 2009; Young *et al.*, 2006).

Figure 3: Individual roles



The ecology within which decisions about risk, trust and relationships are made is complex and subject to change. Our thematic analysis of the evidence under review led to the identification of 11 broad topic areas, which illustrate key features of the decision ecology. These are now explored in turn, starting with the various roles of people involved in the decision-making process, and moving on to consider their motivations and challenges that occur within the ecology.

Older people get help from others to make better decisions

A range of people are able to assist older people in making decisions – better decisions are likely to be made when a variety of opinions and support are drawn on. A qualitative sociological study from Sweden highlighted the importance of informal support networks in advising on important decisions (Duner and Nordstrom, 2007). A participant explained:

'I got sick and ... ended up at the hospital, and then there was talk that I might not be able to manage at home. I haven't made up my mind. I know that I need somewhere else to live. My daughter thinks that I need a different place to live. I believe that my children want the same thing I do.' (woman aged 98 years old, living alone; Duner and Nordstrom, 2007)

Strong informal support networks also make it easier for older people to make specific decisions about care. This is increasingly important given the rise of personalisation, which requires people to make active choices. Two qualitative studies demonstrated that strong informal social networks left older people better able to choose cash payments over council-managed services. These relationships enhanced older people's access to information about which services to purchase (OPM, 2011) as well as practical support (that is, writing cheques) (Ipsos MORI, 2011). Strong informal social networks also increase choice in spending personal budgets because they give older people a higher level of awareness of the services available. Quantitative evidence indicates that budget-holders relied on word of mouth and trusted third parties as their main sources of information about different suppliers and helpers (Ipsos MORI, 2011; Porter *et al.*, 2005).

Specific role of neighbours

A literature review by Age UK examined the specific role that neighbours played in the lives of older people (Harris, 2008). The role of neighbours is distinct from family support or formal services. Rather than being obligatory, support provided by neighbours tends to be driven by values, underpinned by notions of citizenship and kindness. This has intensified since connections between neighbours have become less visible as a result of community design, the closure of community spaces (for example, libraries) and the rise in car use rather than public transport or walking. Harris (2008) argues that neighbouring has become more purposeful and deliberate, undertaken by people actively choosing to be kind. Age UK's literature review found that neighbours functioned at a number of levels: providing emotional aid (for example, advice about family relationships); small services (such as lending household items or helping to write cheques); large services (such as regular housework and healthcare); financial aid (including gifts and loans); and companionship.

Non-specialised, low-level acts of caring which do not take up much time, effort or specialist knowledge may best be provided by neighbours rather than by remote family, friends or professional services. Indeed, some older people reported preferring the unpredictable or spontaneous social support provided by neighbours who 'just pop in'. This type of connection was perceived very differently from having to have help from a service or agency (Nocon and Pearson, 2000). Apart from the direct benefits implied by specific acts of neighbouring, there are also psychological and disease-related health benefits for older people. For example, there seems to be a positive association between 'belongingness support' (which includes talking with friends or neighbours) and health outcomes (Tomaka *et al.*, 2006 cited in Harris, 2008). The risk of Alzheimer's disease is twice as high in older people who are lonely as it is in those who are not (Wilson *et al.*, 2007 cited in Harris, 2008), and research from Australia concluded that the presence of discretionary friendships, rather than family, contributed to longer survival in older people (Giles *et al.*, 2005).

Role of non-kin support

In light of the potential strain on family members of providing care, it is important to consider the role of non-kin support such as independent supporters and volunteers. The advantage of strong non-kin networks in older age is emphasised by a range of studies (Gray, 2009). Gray (2009) presented evidence that personal communities of non-kin were replacing the roles and support networks that kin used to provide. In some circumstances vulnerable people were more likely to trust acquaintances or strangers than care workers or friends (Furedi, 2011). Indeed, some older people expressed a preference for 'independent' support from carers who were unbiased by regulation and corporate risk avoidance and who made them feel 'less of a burden' than family members (Gandhi and Bowers, 2008). The volunteering that usually characterises 'independent support' is also valuable beyond the benefit it provides to older people. It represents an act of citizenship and can save public money by providing support that might otherwise be paid for (Harris, 2008).

Achieving rapport between volunteers and older people is hugely important. Age UK interviewed older people and found they had more trust and confidence in volunteers than in other service providers:

'I felt very supported by them ... felt a spark between me and the [volunteer] team. We had a laugh. They are human ... treated me with dignity and respect... I felt bullied by the rehab team – bullied to go into the kitchen and cook, information had not been passed onto each other. For three weeks I had to keep telling them what my situation was – treat me like I was stupid and incapable.' (quoted in Bowers *et al.*, 2006, p. 5)

Participants in the Age UK study felt they could discuss things with volunteers that they were uncomfortable discussing with family (Bowers *et al.*, 2006). This demonstrates the value of 'independent' actors who are viewed as impartial and non-judgemental and who have no 'hidden agendas' or 'family baggage' (Bowers *et al.*, 2006).

Volunteering is beneficial to volunteers as well as older people. We identified several qualitative research studies in which volunteers described how much they valued using their skills, ideas and common sense for the benefit of others, and the way in which volunteering had strengthened or developed new skills that would be useful elsewhere in their lives (Bowers *et al.*, 2006; Brodie *et al.*, 2011). Volunteers also noted the value of offering their time without charge, and said that being paid for their time would have diminished the reward (Brodie *et al.*, 2011).

Examples of voluntary support include the 'circles of support' method, which provides a form of support that encourages decisions to be made using positive risk-taking. This involves enabling vulnerable people to interact with strangers as well as family members and formal carers, to ensure there are some actors involved in their care who are not inclined to be overprotective or as emotionally involved in the decisions (Faulkner, 2012).

Wider community

Communities potentially offer a source of flexible and personal support for older people. The importance of strong social networks in older age has been stressed in both academic and non-academic sources (see Bowers *et al.*, 2006; Clifton, 2011b; Harris, 2008; Requena, 2010). Churches, sports clubs and informal ties to family and friends all provide important support in decision-making and care, and provide access to social capital that is correlated to higher levels of wellbeing, self-worth and agency (Gray, 2009). Davis and Ritters (2009, cited in Clifton, 2011b) found that older people preferred to receive information face to face, within their own communities and from people with whom they had a pre-existing relationship and could trust. Behavioural economic research supports this, showing that people do not generally use factual information to make rational decisions about the options available to them. Instead, they tend to observe and copy others (Ormerod, 2010). Wider community support is also valuable for older people with specific health conditions, for example, dementia, that involve significant care needs. The informal watchfulness provided by neighbours, friends and other members of the community (for example, shopkeepers) is valuable in that in-depth knowledge about older people's routines and habits can inform and support decisions about care and managing risk (Gilmour, 2003).

The value of community networks is corroborated by literature detailing the negative impact on decision-making that can result from their absence. Isolated older people have less information about services and social opportunities because they are detached from word-of-mouth networks. Isolation can be exacerbated by the closure of local community spaces such

as post offices, banks, libraries or pubs (Clifton, 2011b) and is a particular feature of ageing. Surveys of older people in England show that at least 10 per cent are isolated and a similar proportion report being lonely. These figures increase among the oldest age groups, with 30 per cent of over-80s having limited access to services such as shops and GPs and 25 per cent being cut off from family and friends (ODPM, 2006, cited in Clifton, 2011b). One study that interviewed service users in London identified three ageing-related life events that could act as triggers for social isolation: a spouse dying or going into care; falling ill and becoming less mobile; and retirement and losing connection with colleagues (Clifton, 2011b).

Decision-making is relationship-specific

Different actors provide different types of support for older people and therefore make different types of decision. Decisions relating to older people's care are not restricted to questions of practical and physical support, for example, helping with cooking or driving, but also extend to emotional, cultural and spiritual support (Gandhi and Bowers, 2008).

Much of the academic social care literature we reviewed drew a clear distinction between people making decisions about providing emotional support to older people and people making decisions about providing physical and practical support to older people (see Young *et al.*, 2006; Funk *et al.*, 2009; Vollan, 2011). However, there was uncertainty about sources of emotional and practical support. Some evidence suggests that family members, particularly spouses, children and siblings, were the primary providers of emotional support (Keating *et al.*, 2003). However, there is conflicting qualitative evidence suggesting that where older people received support from relatives who were not living with them, it was more likely to be functional than emotional (Allen *et al.*, 1992). This underlines the fact that it is not possible to generalise about the type and extent of family support that older people receive.

The role of the wider informal social network (friends and neighbours) is similarly contested in academic and policy literature. A range of studies has considered the role of informal social networks in maintaining and improving mental and physical wellbeing (see, for example, Barrow and Harrison, 2005; Netuveli *et al.*, 2006; Young *et al.*, 2004), but the overall picture is inconclusive. One sociological study indicated that decisions made by friends and neighbours around supporting older people were restricted to whether or not to assist with 'back-up' care such as helping with heavy shopping, housework or gardening (Nocon and Pearson, 2000). It appears that the wider social network does not provide an adequate substitute for family or formal care and is less likely to provide emotional support. Indeed, one qualitative study found that in a mixed-age new development in Brisbane, Australia, older people were on friendly terms with their neighbours, but their relationships rarely progressed beyond basic niceties (Walters and Bartlett, 2009).

Support provided by different actors is fluid

Assumptions about the roles different actors play in older people's lives are further challenged by how often those actors slip in and out of each other's lives. Much literature focuses on fluidity in the formal social care sector, driven by high staff turnover rates that place additional caring responsibilities

on family and friends in order to fill short or long-term care gaps – it has been estimated that social care will require between 0.5 and 1.5 million additional recruits by 2025 to meet demand (Clifton, 2011a). Furthermore, many people with caring responsibilities do not identify themselves as carers, preferring to see themselves primarily as a son, daughter, spouse, parent or friend (Human Resources and Skills Development Canada, 2005).

In this context, the roles of paid and unpaid, formal and informal, familiar and unfamiliar are increasingly fluid. This often points to a more significant role for family and friends or the voluntary sector (Clifton, 2011a), but is not always the case. Some evidence has demonstrated that the caring neighbour image of the local friend providing semi-formal care can be reversed. For instance, an older person being visited by pharmacy staff delivering medication (Harris, 2008) illustrates the way in which the medical practitioner can become a source of social contact and support.

What motivates formal or semi-formal actors in the decision ecology?

Kosny and Eakin (2008) considered what motivated actors in the decision ecology of ageing. Why did formal and informal carers want to help and support the people around them? Through an ethnographic study of three non-profit care providers, Kosny and Eakin (2008) found that motivation of formal workers and semi-formal volunteers in caring professions was based on the existence of strong values that guided their work choices and were core to their personal identity. Their work with older people was 'more than just a job'. The relationship between the identity of people working in these roles and the nature of their work might have had a considerable impact on perceptions of risk in the workplace (Kosny and Eakin, 2008). That formal or semi-formal carers were often driven by values and had chosen to pursue a career in care arguably made them more likely to accept the challenges of caring for older people than friends or family who had not made an active choice to provide support.

Formal carers can make the wrong decisions

Despite the advantages of professional carers being driven by an ethic of wanting to offer care, there is evidence that decisions they make are not always ideal. We identified numerous sources demonstrating that formal carers frequently made inadequate decisions about the care of older people, sometimes resulting in damage to wellbeing. A number of studies show how formal carers could reduce people's independence because excessive risk aversion led to unnecessary restrictions (see Buri and Dawson, 2000; Faulkner, 2012; Tadd *et al.*, 2011), although bad decisions were not always the product of risk aversion. One study presented the case of an older woman in hospital being told to soil herself rather than risk falling over by walking to the bathroom (Tadd *et al.*, 2011):

'Can I go to the toilet please?'

'You've got a pad on.'

'Can I have help to the toilet please?'

'If you... (she sighs with frustration) you've got low pressure, when you stand up your blood pressure drops and you'll be falling.' (Observation:

Rehabilitation Ward [Older People], Site 2, Night duty.) (quoted in Tadd *et al.*, 2011)

Risk aversion appears to be a product of an increasingly litigious, blame-orientated culture in which practitioners are anxious to avoid reprimand or punishment. Carr's review (2010) suggests that this means care staff view patients as 'an enemy to defend themselves against'. Technical risk management approaches treat the patient as an object to be assessed rather than as agents in their own lives (Carr, 2010), resulting in the depersonalisation of relationships between patient and carer. Risk-averse behaviours and decisions can also limit social contact and increase isolation. For instance, infection prevention and falls prevention practices may leave older people feeling disempowered, isolated or lonely. One older person explained the loneliness caused by being nursed in a side room to avoid infection:

'You wouldn't want to be in a little room on my [sic] own because you felt lonely, on your own. You're not feeling well. If there's something going on around you that you can watch it takes your mind off it.'
(quoted in Tadd *et al.*, 2011)

Mitchell and Glendinning (2008) argue that personalisation and individual budgets are the products of this risk-averse culture, transferring responsibility for managing risk to individuals and their families so as to minimise the likelihood of organisations being blamed if things went wrong. There is also a tension between providers' 'duty of care' to protect 'vulnerable' individuals and the growing importance assigned to individual autonomy. Balancing service users' rights, autonomy and empowerment with issues of protection in a context of limited resources, increasing public scrutiny and fear of professional litigation is clearly both complex and challenging (Mitchell and Glendinning, 2008).

Informal connections do not necessarily result in better decisions

Despite the value placed by older people on low-level informal care, there is some evidence suggesting that actors in informal social networks do not always make decisions that improve the wellbeing of older people. Fear often characterises intergenerational relationships, and family members who want to protect loved ones from harm can be both risk-averse and controlling in their caring decisions (see Allen *et al.*, 1992; Faulkner, 2012; Harper and Levin, 2003; Mitchell *et al.*, 2012). For instance, families of people with Alzheimer's and dementia have been shown to give intense supervision to vulnerable family members, aiming to protect them from harm (Mitchell *et al.*, 2012). One study suggested that formal service providers were in fact more likely to enable risk-taking among older people with dementia (Mitchell *et al.*, 2012). Feelings of obligation and duty could also lead to actors in informal social networks (particularly spouses or close relatives) delaying or refusing valuable formal care, often to avoid separation from loved ones (Arksey and Glendinning, 2000).

Some studies challenge the assumption that actors in informal social networks, in particular family members, were more likely to provide kindness and support to people through the process of ageing. For instance, Butt and Mirza (1996, cited in Harper and Levin, 2003) questioned whether

older people living with family members had their needs adequately met, and concluded that family support could contain rather than fully address care needs (Faulkner, 2012). Perhaps contrary to expectations, older respondents to a MORI survey were less enthusiastic about living with their children than their children (Ipsos MORI, 2005). One qualitative study went further, highlighting the dangers of family care when family relationships were distant, negative or even toxic (Allen *et al.*, 1992). It is in these cases that assumptions about caring, loving family members are stretched to their limits. One older person described their fraught experience of having to rely on a distant cousin for access to their pension:

'I have a cousin – we've never been close. He lives in Leeds. He doesn't come often. He writes every week. Once I lost my pension book. Now he keeps it and sends me money. It annoys me – he's bossy. I like to be independent. He lives in Leeds. We didn't know each other very well...' (quoted in Allen *et al.*, 1992)

Conflict in the decision ecology

Older people's wellbeing can be compromised not just by poor decision-making, but also as a result of conflict in relationships. Care from relatives can be a risk in and of itself when family relationships are not at their best. Anecdotal evidence gathered from discussion websites for older people describe times when the wellbeing of older people has been compromised by family members (see, for example, Gransnet, 2011a):

'... my mum is 73, has Alzheimer's and is being abused by her husband. Mum married him about 35 years ago – he is a control freak, bully, manipulator, compulsive liar, has to have his own way or he loses his temper... My sister was then going down every day to put mum's patches on and then she became ill (my sister) and couldn't go down for a few weeks. He went ballistic, calling us liars and saying we didn't care about mum. Since then, he has deliberately and maliciously cut her off from her family and friends – controlling who she sees, talks to etc... The abuse is worsening, the Police say it's not a matter for them, the Safeguarding Adults team insist she's not at risk. He has cut her off from her family, friends, activities, contradicted all the advice of the consultant, has admitted to the Police that he has "told my wife if she EVER sees her daughters again, this marriage is over".' (The Princess Royal Trust for Carers, 2011)

Conflict about who should be in control of decision-making among family members can also lead to strain between family members or friends trying to collaborate in providing support. Informal support networks can also be compromised by interpersonal conflicts, which impinge on the provision of both informal and formal support and threaten family stability for all actors (not just the older person) (Duner and Nordstrom, 2007):

'At the time mum got ill I was saving up to go travelling so I said that as dad was in such a good job I'd stay at home with mum so he could still go to work. However, 4 years on, I'm tearing my hair out. I really feel like I've put myself in this position and now there's no way out.' (The Princess Royal Trust for Carers, 2012)

Conflict in the decision ecology is not limited to family, however. A number of studies explored the difficult relationship between formal and informal actors (see DH and DCA, 2005; SCIE, 2005; The Princess Royal Trust for Carers, 2011), highlighting the difficulties of negotiating the boundaries where formal care ends and informal care begins. Anecdotal evidence reveals family members can feel pressured into taking on a larger share of responsibility than they feel is comfortable or safe, resulting in high levels of stress, as this example demonstrates:

'I am scared to take on my dad in his current condition. I do scare easily and I am totally stressed out my mind. So it is all the more disgusting that the NHS is bullying me into caring. His walking is even poorer now yet they are happy to discharge him to live alone. They don't see, even though I have actually put it in writing to the Ward Manager, that they are putting a very old man with multiple conditions in very serious danger by sending him home.' (The Princess Royal Trust for carers, 2011)

Several studies report that young carers and their families considered the support provided by social services to be intrusive and/or of limited value. Young carers also report that services could be slow and rigid in their delivery (SCIE, 2005). One of the strongest messages arising from a Department of Health consultation on social care priorities was the frustration and anger that so many carers felt about the way they were treated by healthcare professionals. Carers often did not feel valued or recognised as expert and equal partners in care (DH and DCA, 2005). This highlights just how varied the decision ecology around ageing is: some family members reported unwanted pressure from statutory services while others found their presence intrusive or diminishing. This variety of experience indicates the near-impossibility of designing one-size-fits-all provision.

Decisions made affect all the people involved in that decision ecology – the people around the older person also have needs – and the extent and degree of these needs may be finely balanced between different parties (Fine and Glendinning, 2005). People who provide 20 or more hours a week of care are more likely to have health problems, along with those in households with fewer resources (Glendinning *et al.*, 2009; Young *et al.*, 2006). Up to 45 per cent of carers cut back on essentials such as heating or food to provide support to older people (Carers UK, 2011). Compromising the health of carers unsurprisingly affects their ability to provide care. Beach *et al.* (2005) found that when carers were at risk of depression or reported physical symptoms of ill health, care recipients were more likely to report that their care-givers had screamed or yelled at them, or spoken in a harsh tone. The importance to carers of managing stress is emphasised by this comment from a carer writing on the discussion forum Gransnet:

'My husband suffered a severe stroke 12 years ago which left him wheelchair bound with severe speech and communication difficulties, I had to become a mind reader but I muddled through getting to know his little ways and what he wanted. I must admit there were times when I was really down, I felt there was no life for me, all work, no play... I soon realised the importance of having some time to myself, it does help mentally and physically.' (Gransnet, 2011a)

Social value of older age

Most literature on decision-making, risk, trust and ageing describes older people as a group that need support and who have decisions made for or about them. However, a number of studies inverted this perspective, instead emphasising the valuable role older people could play in being volunteers, carers and community members in their own right (see O'Sullivan, 2011; Warburton and McLaughlin, 2005). From this perspective, older people's roles within the decision ecology are that of active agents rather than as passive recipients. The roles that older people might take on have economic and social value, for instance, facilitating female labour market participation by caring for grandchildren while mothers work, strengthening intergenerational relationships by acting as mentors to young people and providing support for other older people by giving lifts, gardening, shopping and taking care of pets (Warburton and McLaughlin, 2005). These activities not only support sustainable, healthy communities and families but also have reciprocal benefits for the older people themselves who feel productive, valued and maintain strong social networks as a result of their activities (Gray, 2009; Warburton and McLaughlin, 2005).

Discussion

Our depiction of the decision ecology is inconclusive because the landscape is so diverse. While we found convincing evidence of the positive influence of being well socially networked, we also found that advice and influence gained from informal networks was not always conducive to the best outcomes in decision-making. Similarly, while much of the literature under review stressed the significance of supportive family relationships, we also found evidence that family care could be overcontrolling, risk-averse and even abusive. The picture was correspondingly ambiguous and equivocal in relation to formal care providers. While the values and motivation of professional carers appeared to put them in a good position to make the best decisions, the need to adhere to technocratic approaches and practical pressures often seemed to get in the way.

That the decision ecology is characterised by such ambiguity is an important, if not transparently gratifying, finding. The evidence clearly illustrates that individual experiences vary enormously, and that for every negative experience of family, formal or informal care decisions, there will be contrasting positive experiences. The move to position older people as active agents rather than passive recipients is clearly, in broad terms, a good thing that we should encourage, but it is also important to take note of those older people who still require support from others in making active decisions. The following chapter looks more closely at the factors that influence decision-making for the different actors within the decision ecology.

5 CARING DECISIONS

This chapter looks at the factors that influence how decisions are made.

Introduction

Having explored the defining characteristics of the decision ecology, we now turn to consider factors that may influence how decisions are made. We start with a discussion of general factors that may influence anyone involved in caring decisions, and then discuss specific influences on decision-making by people from the four categories outlined in Chapter 4: older people (in need of care), formal carers, informal carers and the wider community.

General factors that may influence caring decisions

Our literature search revealed that a range of general factors might influence any of the actors involved in caring decisions, and add to the understanding of the decision-making process outlined in Chapter 3.

Visual images

A frequently overlooked influence on decision-making is the impact of visual images, which tend to reflect social stereotypes. Analysis of visual images associated with health, wellbeing and ageing revealed a bifurcation, namely (1) images of active ageing including images of physical activity, group activities, the promotion of paid and unpaid work and images of learning opportunities in later life, such as learning computing skills; and (2) health, risk and dependency which included visual images of health risks, common risks associated with safety and security and images of dependency such as the use of mobility aids and dependent care relationships. Old age was primarily depicted as a time of heightened risk, with continual reminders of an ageing body in decline (Martin, 2012).

Grady suggests that 'visual images shape the ways that "we live our bodies"' (Grady, 2004, cited in Martin, 2012, p. 12). So visual images do not merely reflect but also reproduce social differences, influence our bodily conduct and affect our perceptions of risk in everyday life. They may also have active effects, with continual interplay between collective imageries,

identities, inequalities and how we experience and conduct our embodied selves (Martin, 2012).

Cultural perceptions of those in need

In recent years there appears to have been a shift in cultural perceptions of those in need, with a growing trend towards negative framing of vulnerable groups such as older people and people with disabilities. Beresford and Andrews (2012) argue that the government, through the media, has deliberately perpetuated the view of people with disabilities as being workshy, malingering, layabout 'scroungers'. This account chimes with the 'just world bias' perspective that suggests we blame people for their misfortunes because it legitimises the system we live in. Petersen and Lupton (1996, cited in Mitchell and Glendinning, 2008) argue that new public health discourses 'made up' certain kinds of individuals. The ideal of health ageing is an example. The tendency to differentiate between success and failure in ageing (Gilleard and Higgs, 1998, cited in Martin, 2012) can lead to the 'doing down' of other individuals who don't conform to the images of active and healthy old age, and vulnerable adults experiencing widowhood, divorce, social isolation, poverty, dependency and ill health who fail to live up to the ideal are in danger of being marginalised and stereotyped.

Survey data supports the existence of this trend, both from the perspective of vulnerable groups and the community at large. A small consultation conducted by Scope showed that the number of people with disabilities facing hostility has grown by 40 per cent in the first half of 2012 (i.e. February-June 2012). Twenty-five per cent of people surveyed in the latest British Social Attitudes Survey said the that reason people lived in need was because they were lazy or lacked willpower (NatCen, 2012). A Prospect and YouGov poll found that 74 per cent of people thought that we spent too much on welfare and that the government should cut levels of benefits.

Attitude to risk

Attitude to risk is clearly relevant to caring decisions. The approach to risk grounded in cognitive rationality involves collecting and analysing knowledge and using it as part of a formal decision-making process. Its development is predicated on the aspiration to control the world and its uncertainties through the systematic application of knowledge. However, the investment of time and resources required means that this approach tends to be restricted to contexts in which such resources are available and the investments are considered worthwhile, and they are most likely to be used by large-scale bureaucratic organisations.

Douglas (1986, cited in Herring and Thom, 1997, p. 234) pointed out 'as people grow older they are often viewed as vulnerable and at risk, of falling, of hypothermia, of being duped by bogus "officials" claiming to be from the gas board.' It is suggested that this stereotype is misleading, and for many older people who lead active lives, and who have the assistance of friends, neighbours and relatives, it is not an accurate representation. Nevertheless, the image of the frail, vulnerable older person is a powerful one. According to Norman (1980, cited in Clarke, 2000), such stereotyping infantilises and patronises older people and prevents them from making choices about their lives. Douglas argues that labelling vulnerable people as 'at risk' 'justifies bringing them under control' (1986, cited in Herring and Thom, 1997, p. 57).

Mood

We found evidence indicating that positive moods were correlated with taking risks – people in a positive mood perceived the environment as a safe

place and adopted top-down processing in making judgments (Forgas, 1994; Isen, 1993; and Nygren *et al.*, 1996, all cited in Chou *et al.*, 2007). Positive mood enables a focus on the positive aspects of an outcome; individuals thus perceive the choice as less risky and the outcome as more favourable leading to a greater willingness to take a risk (Isen, 1993; and Nygren *et al.*, 1996, cited in Chou *et al.*, 2007). In experimental conditions it was found that both younger and older adults in induced sad moods were more conservative in making risky decisions than those who were in induced elated moods (Isen, 1993; and Nygren *et al.*, 1996, cited in Chou *et al.*, 2007).

Gender

Research suggests a strong relationship between gender and risk judgements and attitudes (Slovic, 1999). Several dozen studies quoted in Slovic (1999) documented the finding that men tended to judge risks as smaller and less problematic than women. Furthermore, those who judged risks as smaller also tended to be better educated, more affluent and politically conservative (Slovic, 1999). Slovic found that men and more educated, affluent and conservative people had a more measured attitude to risk or were perhaps more likely to see risks as surmountable, whereas women were more likely to see risks as big problems. More generally, Slovic also found that if people wanted something to happen or thought it would benefit them, they were apt to ignore any attached risk (Slovic, 1999).

Factors that influence older people's decision-making

In this section we discuss evidence with a bearing on older people's involvement in decisions about their own care.

Cognitive impact of ageing

Neuropsychological changes inevitably occur with ageing which can be detrimental to decision-making (Denburg *et al.*, 2007; Gutchess *et al.*, 2007; Peters *et al.*, 2007). However, the impact of ageing on cognitive processes is not uniform, and Goldberg (2009) suggests that our minds can in some ways improve, even as the brain shows signs of physical decline. Kovalchik *et al.* (2005) compared decision behaviours in neurologically healthy young and older adults, and reported that decision behaviours were not significantly different between the two groups.

An experimental study found that as individuals got older, they relied more on affective than on deliberative cognitive processes (Mata *et al.*, 2007). Affective processes use gut instinct and cumulatively acquired experience and knowledge. Deliberative decision-making entails more effort, mostly devoted to acquiring new information to inform decision-making. Older people's reliance on affective processes does not seem to result in worse decisions. Several studies indicate that when presented with decisions where it was appropriate to use affective decision processes or where decision tasks were presented unambiguously, decisions taken by young and old adults were not dissimilar (Mata *et al.*, 2007; Zamarian *et al.*, 2008).

Ageing can result in a decline in 'effortful thinking', but being older enables one to benefit from an accumulation of knowledge and experience (Carstensen and Mikels, 2005). Carstensen and Mikels (2005, p. 117) state:

Gains in emotional functioning occur against a backdrop of well-documented declines in effortful cognitive processing.

Some commonplace decisions facing older adults may leave them vulnerable to fraud (Rolison *et al.*, 2011). An important practical challenge is how to implement decision situations that take account of the different cognitive strategies older people use to reach a decision. Indeed, Goldberg (2009) calls for direct government action to educate elderly consumers on how to avoid false advertising and claims and reduce fraud level among that group. More generally, Goldberg (2009) and Finucane *et al.* (2002) propose that governments and marketers should consider the use of decision aids that acknowledge the 'fit' between the decision task and the decision-maker capabilities.

Older people's attitudes to risk

In the everyday lives of older people, uncertainties abound and resources are limited. The behaviour of other people is a common cause of worries. Strategies to manage such worries usually draw on readily available resources: 'relationships, feelings and intuition which underpin both trust (through maintaining close relationships) and distrust (through avoiding threatening individuals and places)' (Alaszewski and Coxon, 2009, p. 201).

In a study examining risk (primarily the risk of falling over) in a day home for older people (Ballinger and Payne, 2002), it was found that the physical consequences of falls were taken seriously, but the psychological aspects were often overlooked (Ballinger and Payne, 2002). The dissociation of the self from the likelihood of falling was observed by Braun (1998, cited in Ballinger and Payne, 2002) from a survey of older people living in residential accommodation in the US. The respondents were more likely to identify other people as at risk of a fall than themselves. This suggests that rather than the risk being independent of the person (or neutral for affect), individuals 'are strongly motivated to underplay their personal susceptibility' (Ballinger and Payne, 2002, p. 309). Health professionals also cite personal characteristics of the older person as increasing the risk of falls (for example, high blood pressure), whereas older people cited external factors (such as 'carelessness of others') (Ballinger and Payne, 2002).

Changing priorities in old age

We found evidence that there are some fundamental changes in old age which affect their priorities and goals. For example, older people tend to focus more on socio-emotional goals than younger adults, for example, socially gratifying encounters with others (Carstensen and Mikels, 2005).

Security

The degree to which individuals feel secure in their lives is related to trust and decision-making capacity. In a Swedish population study of people aged 65 and 75, it was found that those who considered their life 'very secure' were more likely to have confidence in economic institutions, more likely to feel they could master crises and more likely to consider their life meaningful (Fagerström *et al.*, 2011). In contrast, those who considered their life to be 'insecure' were 'less likely to trust their immediate family, less likely to trust friends or neighbours, less likely to consider their functional ability good, less likely to feel economically secure, less likely to have experienced a recent crisis but more likely to expect the world to be chaotic' (Fagerström *et al.*, 2011, p. 1310). As with mood, artificially inducing a sense of security cannot necessarily be achieved through intervention, but it is important nevertheless to understand the influence of variations in perceptions of life security.

Social experience

Walker *et al.*'s (2007) understandings of risk in a health context emerged from social and personal knowledge. In this case, risk was regarded as the result of 'sociocultural, historical and group-specific forces [becoming] sedimented' in the individual's knowledge and emotions. 'Anxiety and trust, rather than "cold" information-handling processes, may well play pivotal roles in the apprehension of risk' (Walker *et al.*, 2007, p. 913). Anchoring and objectification are the two key processes which construct different representations of risk. Anchoring describes the process of new events being moulded to appear continuous with existing ideas; objectification refers to the inclusion of emotional and political elements in the representation of risk. While anchoring involves drawing on shared knowledge from the past, objectification involves drawing on the current experiential world of the particular group (Walker *et al.*, 2007). This work highlights the importance of the historical, cultural context in which older people have lived their lives and the ways in which the experiential world of the specific social groups shapes their understanding of risk in healthcare contexts. It relates to the discussion of narrative that follows, in Chapter 6.

Factors that influence formal carers' decision-making

The evidence we reviewed, including research into individual planning and safeguarding, revealed that high-trust relationships are an essential ingredient in good decision-making practice. Factors that can impede good decision-making include professional bias, organisational culture, snap judgements and specific circumstances (such as a current crisis). These are considered in turn below.

High-trust relationships

A recent consultation on UK adult safeguarding policy showed that for people using services, 'understanding what made them safe required understanding them as people – understanding their personalities, their experiences, their family relationships, their wishes for the future and their past histories of choices' (DH, 2009). Davis and Ritters (2009, cited in Clifton, 2011b, p. 14) found that 'older people preferred to receive information face-to-face, within their own communities and from people with whom they had a pre-existing relationship and could trust.' Research on relationships with doctors provides an example. Whereas older people are generally likely to trust their physicians, there is a strong correlation between lack of trust for one's physician and desiring autonomy over medical decision-making (Kraetschmer *et al.*, 2007). Most patients rejected a purely passive role, but also showed little desire to take full charge (Kraetschmer *et al.*, 2007). Good medical decision-making for patients, especially older patients, requires doctors to build and sustain a clinical alliance with their patients.

Factors that undermine high-trust relationships (for example, staff turnover or perceived professional incompetence) are likely to reduce person-centredness and therefore heighten the likelihood of deterioration in quality of support (Brown *et al.*, 2005).

This range of evidence points to the fact that the social context of relationships is extremely important when framing and understanding risks – something that family, friends and the wider community might take into account but that is easily overlooked by formal carers who can become blinkered by formal risk management processes.

Organisational and professional cultures

The rise of a culture of blame in society as a whole has led to an increase in defensive practice, something we discuss at greater length in Chapter 7. Against this backdrop, there are also particular features of organisational and professional cultures that influence the nature of caring decisions.

Organisational culture can have a significant influence on approach to risk and therefore influence the nature of decision-taking. Factors affecting approach to risk include management strategies, wider professional ethos (Alaszewski and Manthorpe 1998; Alaszewski *et al.*, 1998; all cited in Gilmour *et al.*, 2003), the presence or absence of clear organisational guidance and the degree of trust in colleagues and their support (Robertson and Collinson, 2011.) The length and type of practitioners' experiences may also be important (Mitchell and Glendinning, 2008).

Clemens and Hayes (1997) identified two types of decision-maker: agonisers and snap decision-makers. Social workers tended towards the former, nurses the latter (p. 10). An interesting finding is that social workers seemed more risk tolerant than nurses (Clemens and Hayes, 1997), which may be the product of agonising. Rather than coming to decisions based on a comprehensive understanding of the relevant factors, staff often relied on a composite first impression based on a conflation of several client characteristics, often related to personality (Clemens and Hayes, 1997).

Crisis decision-making

Some caring decisions are taken at times of crisis, for example, the decision to admit an older person to hospital or long-term care. The type or scale of the crisis may influence the decision process. For example, the need for a quick decision may mean that a comprehensive assessment of need is not done. What happens after a crisis often seems to be determined by the degree of confidence about a person's future risk. For example, if someone was admitted to hospital, discharge home might depend on staff feeling confident that there was not a high of them falling again (Taylor and Donnelly, 2006).

Factors that influence informal carers' decision-making

Reciprocity and normative/filial obligations

Reciprocity appears to be a strong motivating factor in some informal care relationships. A study that interviewed carers found that in around half the cases the carers said they took on the role happily or that they wanted to care because they felt it was a reciprocal role. As one daughter attested: "[My mother has] always stood by me, so it was my job to stand by her – to repay her for all she's done for me..." (quoted in Allen *et al.*, 1992). Reciprocity is particularly significant in maintaining friendship ties, in contrast to kin ties that are based on normative obligations and thus seen as both more stable and reliable for support (Peek and Lin, 1999, cited in Keating *et al.*, 2004).

According to Marc Stears (2011, cited in Clifton, 2011a), decisions to care do not necessarily result from a sense of responsibility. Stears described the emergence of what he calls a 'transactional mindset' in the way we live our lives (2011, cited in Clifton, 2011a). He charts the rise of efficiency in a range of spheres – including the workplace, public services and family life – that have undermined a sense of mutual responsibility. However, the character of generational giving and receiving is transitive rather than reciprocal. 'We "repay" the generosity of the preceding generation by giving in turn to our successors' (Moody, 1993, p. 229).

Involvement of the wider community in caring decisions

In Chapter 4 we saw that the wider community can be a very valuable source of support for older people. In this context it would seem a good idea for people with more extensive care needs to maintain their contacts with the wider community. However, support given to service users by the wider community is typically fragile and intermittent, and members of the wider community often have a poor understanding of their needs (IPPR and PwC, 2010). Our review revealed some of the reasons for this.

Fear of commitment

Members of the community who may potentially offer support to older people were frequently discouraged out of fear of making a commitment they could not stick to. One respondent in an Institute for Public Policy Research (IPPR) and PricewaterhouseCoopers (PwC) study on volunteering and public services said: 'There are a lot of people who don't want to be tied down in anyway, they don't want to commit themselves' (quoted in IPPR and PwC, 2010).

Social norms

People have implicit understandings of what society deems acceptable and what can or cannot be asked of family or friends, that forms a basis for their negotiating support (Finch and Mason, 1990). Whether people decide to offer support depends on the local social environment, including how willing others are to provide support, how socially acceptable it is to turn down requests for help and the level of social capital in their locale (Graham and Flowerdew, 2007).

Anecdotal evidence sourced from the Gransnet forum raises the possibility that older people may hold an assumption that inviting people into their homes should be avoided: 'I noticed that many older people, particularly in rural areas have a public social life, they meet people and chat in the street, the pub, WI or at village events but rarely invite people into their house. Once disability makes them housebound they lose their social life and most of their friends because visiting friends and acquaintances at home has never been part of their life' (quoted in Gransnet, 2012a).

Practical considerations

Practical considerations can also stand in the way of people deciding to offer care. Lack of time was one such barrier. Older people participating in the study identified a number of barriers to engaging in paid and voluntary work in retirement including ageism, health, lack of public transport and other access problems, lack of confidence and qualifications and limited opportunities in certain localities (Hayden et al, 1999).

Red tape and bureaucracy can also act as hindering factors. Workshops on volunteering and public services facilitated by IPPR and PwC revealed evidence of this. Insurance and liability were frequently mentioned as constraining factors. As one respondent explained: 'We need to be encouraging something like gardening to help older people who can't maintain their gardens, even if it means having gardening equipment that could be borrowed. The barrier again is fear of something going wrong and liability, health and safety' (quoted in IPPR and PwC, 2010). This demonstrates that perceived or expected barriers play as much of a role as practical ones.

Discussion

Our attempt to go deeper into caring decisions reveals that the overall picture is complex, featuring an interplay of competing influences and conflicting interests. The small, user-led scoping study which found that the professional view took precedence when service users were involved in decision-making (Faulkner, 2012) is a reminder of the inequalities of power in the decision-making ecology.

Professionals tend to believe that their own decisions are guided by the rational application of technical knowledge. It seems that it is time to challenge the myth of technical rationality and to take more account of the role of emotion (for example, feelings about risk) in decisions made about people's care. For informal carers factors such as relationship, reciprocity and obligation influence decisions about taking on and remaining in a caring role that can put considerable strain on their own health and wellbeing. In the wider community, decisions about involvement are affected by cultural norms and anxiety about overcommitting. The evidence suggests that older people primarily use affective, rather than deliberative, cognitive processes in their decision-making, but the decisions they make seem to be no worse than those made by younger people.

We found evidence that the primary aid to good decisions is high-trust relationships. Where alliances are formed on the basis of reciprocal trust, the likelihood of beneficial decisions being made is enhanced.

6 MAKING SENSE WITHIN THE DECISION ECOLOGY

What is the role and potential of narrative in effective decision-making and change?

Introduction

The changes that later life inevitably brings and the range of possible ways of responding to and dealing with these changes can carry considerable stress. We have seen in the previous chapters that individuals inevitably face a myriad of choices in how to negotiate the challenges, opportunities and demands of being older and potentially needing help. The range of decision-making possibilities and the lack of a concrete and reliable road map with which to navigate these options is in itself a stressful set of circumstances to have to find a way through. Doing so may require individuals to draw on inner resources and develop means of making sense, finding meaning and building coherence. In this chapter we consider the ways in which narratives can function as vehicles for imparting information and mitigating choice-related stress, discuss how dominant narratives about older people may have an impact on them and examine the role of narratives and storytelling in bringing about more effective decision-making and change.

The power of narrative

The power of the stories we tell and hear about ourselves and others, and the ways in which they are used as tools for making sense of life, cannot be underestimated. There is a growing body of psychological and neuroscientific evidence brought together by Jones and McBeth (2010) that identifies narrative as being the primary means by which individuals process information and form beliefs. Additionally, narrative is a key medium for the proliferation of cultural norms and primary discourses. Simmons (2000) captures the reasons for this through the description of 'push' and 'pull' strategies: influencing people through scientific analysis is a 'push strategy',

assuming that cold, hard facts will convince, whereas the use of narrative is a 'pull strategy', in which listeners are coaxed or even disarmed into imagining outcomes toward which facts would not lead.

Mitigating stress

We found an array of evidence that indicates that narratives and storytelling can help older people, their families and carers (paid and voluntary) to mitigate the stress inherent in living within a complex and uncertain ecology of decision-making. It is almost certainly a truism that narrative communication techniques are better at holding attention than the presentation of technical material (Golding *et al.*, 1992, cited in Jones and McBeth, 2010). Many studies have shown this. For example, Slovic (1999) reports that 'risk statistics' often did little to change people's perceptions because of the fact they did not engage people on an affective level or speak to their values. In contrast, narratives of risk carried the power to change attitudes and behaviour because they tapped into non-rational, values-based and affect-driven factors (Slovic, 1999).

Communicating information through narrative

Further evidence indicates that there is considerable potential for narratives to be used as vehicles for conveying important information about risk, as identified in Ricketts' doctoral dissertation, 'The use of narrative in safety and health communication' (2007, cited in Jones and McBeth, 2010). Ricketts found that when individuals received a safety warning in narrative form, they were 20 per cent more likely to follow it than those who received the information in an abstract form. This finding is supported by a further piece of research conducted by Finucane and Satterfield (cited in Jones and McBeth, 2010), who demonstrated that narrative was a more powerful means of both conveying and obtaining information than didactic techniques. Mittendorff *et al.* (2006) found that narratives were the most effective means of converting tacit knowledge into explicit knowledge. Therefore, narrative communication is a vital means of empowering older people and those in their support networks because it carries the capacity to take hold within their emotional and values frames, thereby allowing them to better understand the nature and implications of the decisions they face.

Whose story is it?

It is important to make a distinction between the stories we construct about ourselves, those told about us and the broader societal narratives about particular groups or types of people (such as older people, carers or people with dementia) (Riessman, 1993). Jones and McBeth (2010) argue that all narratives share certain structural features, namely, plot, characters and a moral. Under this framework, plot configures causal explanations, characters are generally categorised as heroes/allies, villains/enemies or victims, and the moral of the story equates to the life lessons learned through the processing of the narrative.

It should be noted that the notion of 'plot' is itself problematic in that power structures are often implicit in the construction of meta-narratives. Jones and McBeth (2010) highlight this by referring to 'canonicity' and

'breach' – canonicity being the extent to which narratives reflect the status quo, and breach referring to stories that deviate from the status quo. They note that stories tend to be more persuasive or convincing when the breach is great. In a similar, although differently framed analysis, the predomination of 'dominant' plot construction has been described by Bamberg (2005) as a 'master narrative'. Master narratives constructed by professionals, the media and society in general about older people or their carers can add to the burden of stress and difficulty in both feeling in control and being able to act assertively. Attempting to behave in a way which is in tension with a master narrative (that is, older people as defenceless and vulnerable) can be extremely challenging or even impossible. Andrews (2004) describes the critical importance of 'counter-narratives', which less empowered or excluded individuals or groups can use to challenge master narratives, thereby gaining more autonomy and being more empowered to make decisions outside of what may be possible within a choice structure primarily defined by the overarching master narrative.

Stories as mechanisms for growth and change

Jones and McBeth (2010, pp. 343–4) identify three further ways in which the content of a narrative can relate to its capacity to be an effective mechanism of growth and change:

- Narrative transportation: the degree to which the reader identifies with protagonists and gets lost in the story. The more the listener is affected by the narrative, the more likely they are to be persuaded by it.
- Congruence/incongruence: the extent to which the story makes sense according to the listener's experience of the world. The greater the congruence, the more persuasive the narrative.
- Narrator trust/credibility: the more the narrator seems trustworthy and credible to the listener, the more convincing she or he is likely to be.

In identifying these narrative features, further questions can be raised about whose narratives are being told and to what end. It is possible that the impact of having one's story of, say, illness and recovery, or that of a loved one constructed and framed according to the perspective of a third party, whose agenda may be in opposition to one's own, could itself be a precipitant of risk or damaging to a sense of trust. This holds whether or not a person is explicitly aware of the narrative view held about them. Professionals have the choice to assist older people in structuring and telling their own stories as a means to gain and maintain autonomy and to make decisions with confidence (Kroode, 2006). In the context of cancer patients facing existential crisis, Ten Kroode notes that 'the most natural ladder [professionals] have is our capacity to listen heartily to their story or narrative' (p. 51). The psychologist Timothy Wilson (2011) further argues that the stories people construct about themselves are central to identity, and, in keeping with the ethos of narrative therapy (Holmes, 1999), suggests that we need to engage with these internalised narratives in order to alter and improve damaging and negative behaviour. Narratives are therefore essential in understanding the processes by which individuals and organisations structure their understandings of risk, develop their strategies for engendering trust and make positive decisions about their lives.

A powerful or shocking story about a public service failing to protect vulnerable children (for example, the 'Baby P' case) has the capacity to take

hold in the public consciousness and override understandings of the factual evidence (that is, that such occurrences are extremely rare). Because of the tremendous power of narrative to trump 'facts' in this way, there is a real possibility that the preference for relying on word of mouth (that is, cultural narrative) as the primary source of information is a key factor in decline in trust in public services. This explanatory link was identified by Ipsos MORI in a report on 'socio-political influencers' (Duffy and Pierce, 2007). Conversely, restitution narratives, which optimistically emphasise asserting control and becoming well, can significantly improve the social positioning of older people and serve to augment their armoury of resources for making positive choices and finding ways to meet their needs (Lupton, 1999, cited in Mitchell and Glendinning, 2008).

There is a wealth of supporting evidence demonstrating the transformative and emancipatory potential of narratives in enabling older people to accept negative life events and to make positive decisions in the face of them. Participating in a facilitated storytelling group was shown to have positive effects on self-efficacy, mood, stress, coping with stress and life satisfaction in a small study involving patients with cancer (Crogan, 2008). For those experiencing chronic illness, telling and sharing stories in a supportive environment was shown to enable new meaning and understanding to emerge, and to bring about the illumination of future possibilities not previously considered (Clarke *et al.*, 2003; Leight, 2002). Some evidence indicates that this is particularly powerful for women (Leight, 2002), although we should not assume that men are less able to benefit from such approaches.

Discussion

In the face of the picture painted by this evidence, it is vital that any attempts to communicate messages around risk consider how best to do so using narrative means. Ensuring that narratives are derived from lived experience, and that transportation, congruence and narrator trust are maximised, is paramount if stories are to be used to transformative and empowering ends. Furthermore, efforts to challenge negative, marginalising and stereotypical meta-narratives about older people must be seen as everybody's social responsibility, and require the engagement of the media, policy-makers, third sector organisations and the community at large. Doing this will be dependent on the identifying and using means by which older people's 'counter-narratives' and real experiences can be transformed into stories that can capture the public imagination and replace more damaging discourses.

7 RISK AND TRUST

What impact do issues of risk and trust have on the care of older people?

Introduction

Our analytic perspective on decision-making requires us to accept that human decision-making is complex, often arises from socio-emotional factors, and is anything but a simple purely rational process. We have seen that the *ecology* within which decisions by and about older people and their care needs are taken is also complex, and that multiple factors have an impact on how decisions are made. We now turn to explore issues of risk and trust in more depth, exploring their impact on the care of older people. The majority of the evidence reviewed here comes from the literature of social care because our literature search resulted in the identification of sources from this body of evidence.

Risk and trust: central pillars of social care

Effective decision-making in social care no less than in medical care requires a *partnership* between the person needing care and their carers. This requires trust, and no more so than in the case of vulnerable older people, where the person needing care must trust their carers, whether family members, neighbours, members of the community, and especially, professional carers. To achieve this it is essential that risks are managed optimally – not just to protect carers, but especially for the best interests of the person in need of care.

Risk

Risk can be considered from both individual and broader societal level perspectives and there is multi-disciplinary interest in the place of risk and trust in society. It has been argued that trust is crucial to welfare states and social institutions, and that this is undermined by a neoliberal emphasis of individuals, rational actors and risk (Gilson, 2003). Risk has also been conceived as a strategy for social control and regulation in Foucault's notion of *governmentality* (Adams, 2001).

According to one understanding of risk (Adams, 2001), the concept of risk is used to establish boundaries between the self (and the safe, the familiar) and 'the other'. In this sense, 'risk' is defined as an objective threat, hazard or danger that must be mediated or controlled. This understanding of risk is associated with the anthropologist Mary Douglas (1966, cited in Adams, 2001), who argued that the body is used symbolically and metaphorically in discourses and practices that surround risk. Douglas argued that society's conceptualisation of the body mirrors its anxieties about policing its boundaries.

Perhaps this conception underlies the widespread, but in our view, mistaken, idea that those with responsibility for the care of other people should, as a top priority, attempt to eliminate risks for their people, and only after that has been achieved, actively seek to pursue their 'positive' wellbeing.

A dual conception of risk operating at both highly personal, subjective levels and in a more objective, social setting has been developed by Lupton (1999, cited in Mitchell and Glendinning, 2008), who highlighted two broad approaches to conceptualising risk: 'technico-scientific' and 'socio-cultural'. Technico-scientific approaches focus on calculations of risk probability, measuring hazards and dangers, and are prominent in a number of scientific and social science disciplines. These approaches aim to be 'scientific' and establishing accuracy is central; risk (severity of potential harm, as well as its likelihood) is viewed as largely objective, and independent of socio-cultural ideas and practices. Risk factors can be identified (by 'experts' through their 'expert' knowledge) and measured by assessment tools. In contrast, 'socio-cultural' approaches, while recognising that the likelihood of particular outcomes may be assessed objectively, place great importance on social, cultural and economic structures, processes and interpretations (Mitchell and Glendinning, 2008).

Taylor-Gooby (2002) takes this separation between quantifiable and less easily quantifiable risk further, suggesting that there are actually two different paradigms – risk and uncertainty – that capture risks or dangers. 'Risks' are rational, measurable and calculable and are often associated with competence, whereas dangers relating to broader social, moral or psychological unknowns are 'uncertainties' rather than risks (Taylor-Gooby, 2002).

The idea that there may be a subjective element to the perception and definition of risk is taken a stage further in literature exploring the differences between expert and non-expert use of the term 'risk' (see, for example, Clarke, 2000; Gray, 2009). Here it is argued that the apprehension of risk is, for instance, different for a family member than for a formal carer. A professional might perceive risk in an older person choosing to walk unaided to the bathroom because the person might fall, whereas for a family member, the risk in not allowing an older person to take him- or herself to the bathroom might loom large, especially if the person was usually independent and active.

When considering risk in the context of vulnerable older people it is important to recognise that every decision we make carries a risk, including decisions directed to minimising risks. It would be possible to eliminate entirely the risk of a person falling over (whether they were vulnerable or not) only by ensuring that they never walked – and that could hardly be in most people's best interests.

Risk needs to be managed both at the social policy level and at the individual decision-making level, by recognising that there is subjectivity as to which risks should be avoided, and which are worth taking. The bottom line

is that in the care of older people risk should be managed primarily for the wellbeing of those people, and this may sometimes mean that risks should be taken, which, as things are now, would be avoided in the name of 'defensive' practice.

Trust

Trust and risk are related in that without risk there are no grounds for trust (Walker *et al.*, 2007). As with 'risk', 'trust' means different things to people in different social contexts, and conceptions of it develop with social change. The sociologist Anthony Giddens argued that in traditional societies people were unquestioningly trusted to fulfil their traditional obligations, and in our more flexible and reflexive modern society trust can no longer be taken for granted (cited in Alaszewski and Coxon, 2011). Now, trust must be earned and demonstrated through a constant stream of social interactions – from the highly personal to experts to institutions.

We identified various academic papers suggesting that there are different forms of trust (see, for example, Alaszewski and Coxon, 2011; Leung, 2011; Porter *et al.*, 2005; Smith, 2005). A particular distinction is made between generalised trust (trust in people in general) and special trust (trust in known people or particular institutions) (Leung, 2011). This might also be framed as trust in institutions and groups, and trust in individuals. Both forms of trust are essential for the effective management of risk, especially in respect of vulnerable older people. Trust in institutions is essential if older people needing care, care-givers, family, friends and other actors involved in providing support to older people are to interact successfully with formal services (Leung, 2011). Interpersonal, individual trust is also a crucial part of building and maintaining the relationships that are necessary for the care-giving, kindness and support that vulnerable older people especially need.

It is important to recognise that, although trust is often mutual, the person giving trust – or, 'the truster' – is (on account of that trusting) more vulnerable, because of the possibility of betrayal or abandonment (Porter *et al.*, 2005). This problem is especially acute for older people needing care, because they may start from a position of vulnerability.

A person's ability to form institutional and interpersonal trust depends to some degree on personal experience. Smith argues that trust is a result of socialisation and experience of group membership that allows someone to develop psychological security in encounters with others (Smith, 2005). Trust has been also been described as an outcome of social capital (Gray, 2009). People with strong social networks in which they are able to draw on others for social support and are less likely to experience frequent periods of loneliness might find it easier to develop trust in other people, and even in institutions (Gray, 2009). A study of Japanese rural communities demonstrated that the odds of psychological distress were significantly higher among groups that had low levels of social capital, and as a result, low levels of trust (Hamano *et al.*, 2011).

This has significant implications for older people whose social networks have weakened or diminished. Some evidence indicates that this group find it harder to develop trusting relationships with those who might help and support them to, for instance, remain living at home for longer, or to gather trusted recommendations for other forms of support (for example, gardeners, cooks, cleaners) from friends and acquaintances. A policy-based literature review indicated that weak social capital created suspicion and wariness about accepting help from strangers (Cherti and Clifton, 2009). There are many anecdotal accounts of older people refusing to trust agency-

based care workers to help with their washing, dressing and going to the toilet, and this is an area requiring further research (Porter *et al.*, 2005).

What methods are we currently using to manage risks and to make decisions?

In social care, the prevailing approaches to managing risk and making decision are rather technical and depersonalised (Smith, 2001). Risk management and decision-making sits in the hands of professionals whose impersonal (often paper-based) assessment tools to guide decision-making are detached from the individual or family about whom decisions are being made. In an online forum, one nurse describes using these tools:

‘As for the paperwork, Oh dear! We have a booklet to fill in for each patient, with additional paperwork we download from the computer as it becomes available when “new” assessments and initiatives are devised. Most (not all) is so that we can document in minute detail our responses to these areas of concern, the reason for this so that it can be examined when complaints arise, inquests held, the main thrust being, if it’s not written down then it hasn’t been done! Over the last year or so the amount of documentation has increased alarmingly, there will be no reduction in this as we become more and more reactive to the “blame” culture.’ (Gransnet, 2011b)

Unsurprisingly, this approach to risk management is not sensitive to people’s individual lives and preferences. Each question narrows the choice of the next one so that thinking becomes algorithmic. Such an approach fails to grasp the importance of context, and that in many situations there is no ‘right’ action, but a range of acceptable options.

Highly standardised approaches to risk management may also constrain informal carers. The barrier again is fear of being blamed if something goes wrong. When decisions are made outside of highly formalised systems, risk management may act as a barrier to older people fully participating in their own decisions.

Some current problems with risk management and trust development

One serious problem in current approaches to risk management is the disproportionate focus on ‘technico-scientific’ or measurable risk. This is the type of risk that is more easily quantifiable (for example, has someone fallen over or not?) and can mean that decision-making in this context is more about what will prevent censure, sanction or litigation than what is right (Taylor, 2006). Risk avoidance (or at least the avoidance of certain kinds of risk) can be treated as an end in itself, leading professional and informal carers to avoid prudent risk-taking, instead making decisions based on fear and the ability to justify oneself. A number of studies suggest that care practices were often excessively risk-averse and did not properly balance the risk of physical harm against the risk to a person’s autonomy, self-esteem, sense of identity, and fundamentally, their dignity (Cherti and Clifton, 2009; Taylor, 2006).

A ‘technico-scientific’ approach to risk also tends to give insufficient weight to individuals’ personal preferences and attitudes to risk. One

ethnographic study of risks and risk management in a day hospital for older people found that service providers were orientated towards managing physical risk (for example, reducing the possibility of physical harm in the immediate environment), but older people were more concerned with the risks to their identities that the hospital environment posed (Ballinger and Payne, 2002). Indeed, the professional orientation towards physical, quantifiable risk often conflicts with the desires of older people and can have a negative impact on their emotional and intellectual lives. In formal environments such as care homes, an excessive concern to minimise the risks of physical harm befalling a resident means that people rapidly become less mobile and use fewer life skills than in their own homes. This enforced passivity ignores, for many older people, the need to promote and maintain self-esteem and confidence during the process of ageing (Ballinger and Payne, 2002).

This approach to managing risk and regulation has, ironically, led to an erosion of interpersonal trust resulting from increasing reliance on rules and regulations. We see evidence of concern around the effects of a rules-based culture on individual and organisational resilience, ingenuity and agility. Some claim that our national sense of adventure and entrepreneurship has been diminished, and our sense of community and responsibility has been undermined (Better Regulation Commission, 2006).

Furedi's analysis of this situation is that regulation-based risk management has undermined trust (Furedi, 2011). Older people feel insecure about what to expect from others and are frequently hesitant about trusting people with whom they come into contact because the emotional and personal aspects of relationships have been neglected. There is evidence that some older people 'did not trust care workers or friends but did trust neighbours, some acquaintances and even strangers' (Dixon *et al.* 2010, cited in Furedi, 2011, p. 410). This suggests that an over-emphasis on risk avoidance – whether by a formal carer or a family member, friend, or neighbour, particularly when it restricts older people from doing what they want – damages both formal and informal relationships. Not surprisingly, recipients of care sometimes feel that their best interests are not served by their relatives or by formal services. In such circumstances, 'older people sometimes engaged covertly in risky actions, unbeknown to their informal or paid carers' (Mitchell and Glendenning, 2008, p. 304).

How should we be trying to manage risks and nurture trust?

We agree with a range of commentators who are calling for a major shift in approach, away from extreme risk aversion to one in which *positive risk-taking* is embraced as a means of enabling independence, confidence and self-worth (Kaliniecka and Shawe-Taylor, 2008; Taylor, 2006). We should recognise that 'risk avoidance' carries its own dangers, and that 'embracing risk' can be life-enhancing and generally beneficial. In research undertaken for the Social Care Institute for Excellence, Carr (2010) was able to identify the following core principles for positive risk-taking:

- Involvement of people who use services and those who are important to them – this includes people who form the individual's informal 'circle of support' who are involved from the beginning to gather information, to define what the risks are from the individual's point of view and to discuss ways to enable and manage the identified risks.

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- Contextualising behaviour – this means knowing about the person's history and social environment, their previous experience of risk, what has and has not worked in previous situations.
 - A learning culture – requires a commitment to ongoing learning and the use of reflective practice for people working at the front line.
 - Tolerable risks – negotiating and balancing issues of risk and safety to identify what is acceptable for everyone (the individual and others, including the community) on a case-by-case basis. (Carr, 2010).

At the very least, Carr's principles are a useful starting point to inform wider discussion of how to promote the shift towards positive risk-taking.

There is no quick fix or shortcut to building trust. We identified a recurring argument that we should not be trying to replace interpersonal trust (built through relationships) with 'systematised' trust in institutions (built through regulation-based risk management procedures) (Funk *et al.*, 2009; Parker *et al.*, 2008). Alaszewski and Coxon (2011) introduce the notion of socio-connective trust, emphasising the relative importance of relationship processes over formal care-giving structures. The structure of trust in care-giving is not externally imposed, but constructed through care-givers' tacit ways of thinking, including habituated actions, taken-for-granted assumptions and socio-cultural constructions. 'These tacit constructions influence care-givers' understandings of their role, the expectations they had of themselves/others and the trust relationships that they built' (Ray and Street, 2011, p. 40).

Discussion

It has been said that the degree of civilisation of a society can best be measured by its treatment of the vulnerable. Many older people (including many carers of older people) are vulnerable. Effective proper care of older people is impossible without trust; trust requires an intelligent attitude to risk management, which puts the interests of the vulnerable (cared for and carer) at its heart, and this requires a move away from the blame culture and its attendant cry to avoid risks at all costs. The Mental Capacity Act 2005, which enshrines in law the right for individuals to make their own (good or bad) decisions unless it can be demonstrated in the particular area that they lack the capacity to do so, is a significant step in the right direction. We need to build on this in order to promote positive risk-taking, while providing appropriate protection for those in need of it.

8 RESPONSIBILITY IN AN AGEING SOCIETY

Who should take decisions and who should take responsibility for them?

Responsibility in a state of flux?

An issue arising from our discussions of risk, trust and decision-making is where the responsibility for making those decisions should lie. The depiction of the decision-making ecology in Chapter 4 illustrates the complexity of the arena of responsibility and accountability. A principal challenge is that there is a multitude of actors – institutions, service practitioners, family, friends, the wider community and older people themselves – involved in taking decisions. Many of the decisions taken have knock-on effects for other people who have financial, social and emotional stakes in the outcomes of those decisions. Given this complex set of relationships and interests, it is obviously difficult to determine both who should take decisions (as so many players have an interest) and who should take responsibility if things go wrong (if multiple actions from different people contribute to the result).

This complexity is not unique to this context but is nevertheless a significant challenge for policy-makers and others seeking to improve the quality of social care. Movements towards personalisation in formal care mean that greater responsibility for managing risks is being passed to individuals and service users (Mitchell and Glendinning, 2008). Choice and control have become key tenets of the government's approach to ageing and social care, and this is reflected in policy initiatives from direct transfer payments to personal budgets. According to a Department of Health report into safeguarding and personalisation (Simpson, 2010), however, it is not entirely clear who is responsible for managing risks with the new personal budgets. They acknowledge a 'misconception that some people will be left unsupported, taking full responsibility for managing risk alone' (Simpson, 2010, p. 7).

We found evidence of carers feeling very much as though they had been left with little support and too much responsibility, illustrated in this account from a family carer:

'This is not medical or social work – this is just plain manners but neither NHS nor SS [social services] are overburdened with manners. They are so sure of the power of emotional blackmail that they don't care that they could be putting the patient at risk of being left home alone. They don't consider the damage to the health of the carer. They just want a discharge.' (The Princess Royal Trust for Carers, 2011)

We also found evidence that older people frequently had little say in actions that directly affected their lives and the care they received. This is particularly evident in cases of dementia, where formal providers rarely considered the views of service users (Kirkley *et al.*, 2011). The tendency to restrict older people's responsibility also extends to decisions not directly related to health and social care. In a study of care homes, it was highlighted that rather than try and involve residents in banking and asset management tasks, key financial decisions were regularly handed to family members to deal with (Tilse *et al.*, 2011).

It appears, then, that older people are expected to take greater responsibility for managing their own lives while at the same time continuing to be controlled and 'safeguarded' by those who perceive them to be a risk to themselves and/or others. Giddens has described this contradiction as 'the ambivalence at the heart of modernity'. Such ambivalence is borne out most strongly in the use of individual budgets, where welfare agencies and practitioners struggle to balance the need to fulfil their 'duty of care' to vulnerable people while still respecting the transfer of responsibility (Kemshall, 2002, cited in Mitchell and Glendinning, 2008).

Who should be responsible?

With different actors vying to acquire, retain and sometimes pass on to others different elements within the decision-making process, it is imperative to determine who in the decision ecology is best placed to take on and allocate these different responsibilities. Many people would argue that it makes sense for older people to retain responsibility for decisions affecting their own lives, wherever possible. The personalisation, choice and control agendas place the individual service user at the centre of decision-making in formal social care, in part because it is seen as a necessary step towards the empowerment of older people. According to a national survey undertaken by Ipsos MORI (2006), just over 80 per cent of people felt that they would like to be able to make decisions about their own lives should they become disabled or develop a long-term health condition.

The shortcomings of paid and unpaid carers can provide additional reasons for older people to retain responsibility for decision-making. As pointed out in Chapter 5, the judgement of formal carers can be skewed both by a poor understanding about the desires and needs of service users, and by their own interests. For example, many formal carers and their agencies seem to be fixated with minimising risk, often at the expense of older people's independence and quality of life (SCIE, 2010). The burden of accountability that follows from responsibility means that decision-making in formal services is often more about what is defensible than what is right (Taylor, 2006).

The emotional involvement of unpaid family carers with the people they are caring for can cloud their judgement and heighten their sensitivity to risk (Walker *et al.*, 2007, cited in Mitchell *et al.*, 2012). As a result, care can quickly turn into 'containment' (Harper and Levin, 2003). Unpaid carers have

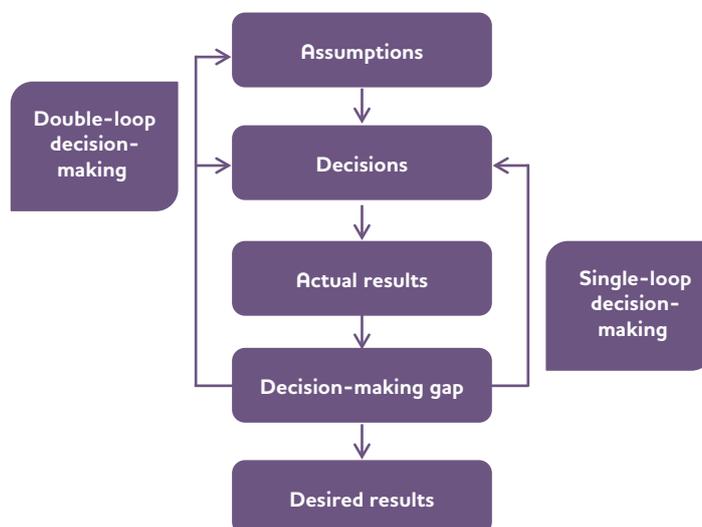
needs and interests of their own, and these may conflict with the needs and interests of those they care for. The same goes for the wider community, whose support for older people can be fragile and intermittent, and who often have limited understanding of the needs of older people (IPPR and PwC, 2010). However, it is important to recognise that in many cases – for example, where an older person is caring for a spouse or partner – the life of the carer and the person cared for are interwoven to such an extent that decisions about the latter will have major implications for the former. A further complexity is that when the balance of give and take in a long-standing relationship is altered by the need for care, the needs and interests of carer and person cared for may conflict. Thus, although there are good reasons to give older people primary responsibility for making their own decisions where possible, there are many situations where it makes sense for other people to be involved in decision-making.

Assistance with decision-making can be extremely helpful, for instance, when choosing which care services to purchase. Findings from a recent Office for Public Management study (2011) indicated that family relationships and wider social networks were important both in encouraging people to choose personalised care and in helping them to select the most suitable service providers. Likewise, an Ipsos MORI (2011) survey found that budget holders were receiving useful information via word of mouth and getting help from relatives on small tasks such as writing cheques and filing invoices.

Double-loop decision-making and distributed responsibility

One model for allocating responsibility is that of ‘double-loop decision-making’. Based on Chris Argyris’ (1976) original work on ‘double-loop learning’, this approach emphasises that the beliefs and assumptions that underpin people’s decisions should be questioned if the desired results do not occur. This is in comparison to ‘single-loop decision-making’ where only discreet decisions and actions are analysed (see Figure 4 below³). In the context of allocating responsibility in an ageing society, double-loop decision-making means not only trying to adjust decisions following mistakes, but also scrutinising assumptions about who should be making those decisions to begin with.

Figure 4: Double-loop decision-making



In practice, this approach would bring different stakeholders together – older people, family, friends, neighbours, formal carers and others – to consider and take apart the rules and assumptions underlying how decisions are made. This might include scrutinising the organisational culture of the formal care service, looking at the unseen practices of control witnessed in family relationships and objectively assessing the capacity of older people to make various decisions on their own.

Although this kind of introspection could be uncomfortable for many people involved in the process – among other things it would ask those currently in control to justify their positions – double-loop decision-making allows for a more honest debate about how much responsibility each party, including the older person, should have in making decisions about their lives and the care they receive. In short, it enables those involved to consider the true size of the older person's decision-making 'fit' and so distribute responsibility.

One option for applying this model would be for central and local government agencies to take ownership of enacting the double-loop process. Following a discussion with all stakeholders, they would set the agreed parameters of decision-making within which older people would be responsible and accountable for their own actions. Potential vehicles for delivering this model and distributing responsibility include the growing numbers of 'circles of support',⁴ which bring vulnerable people into contact with strangers who are in a better place to make more objective judgements. It should be noted that using the double-loop decision-making model lends itself to application in formal care settings, but may be less suitable for use in informal or unstructured settings.

Shared responsibility

It is clear from our discussion of responsibility for decision-making that there is no simple solution to where responsibility should lie. It seems that responsibility should be distributed in such a way that complements this intricate network of support and that takes into account the size, big or small, of the decision-making 'fit', that gap between older people's decision-making capabilities and those required to meet each task. In other words, responsibility should be distributed and shared, with older people and their families being actively engaged in decision-making, while maintaining access to appropriate support and assistance.

In practice this is not easy, especially where people's mental capacities are disabled by, for example, dementia or mental illness. The Mental Capacity Act is an attempt to empower people with mental disabilities to make as many decisions for themselves as possible. Even when people are mentally capable, but old and frail, there is a tendency for paid and unpaid carers to take over decision-making, and the principles of the Act are a useful point of reference for carers of vulnerable older people in general.

Discussion

Much work has been done in fields such as learning disability, mental illness and dementia care that is relevant to vulnerable older people in general. The person-centred, relationship-focused partnership approaches developed in dementia care (Downs and Bowers, 2008), which respect the rights and take account of the abilities, as well as the disabilities, of vulnerable people, offer many ideas about ways to share responsibility for decision-making in practice.

9 CONCLUSION: WHAT THIS MEANS FOR POLICY AND PRACTICE

The expected large-scale rise in the proportion of older people in the population over the next 30 years will inevitably bring challenges. The pressure this will place on public services, particularly in the current context of austerity measures, raises questions about how to provide for them, and particularly how to ensure that best use is made of our limited resources to provide good quality care for older people. In this review we have focused on optimising decision-making through building trust and promoting an intelligent approach to risk management in the care of older people.

Demographic change on this scale means that the provision of care and support is in need of review. In part, this means understanding the new role of professional and formal care in this context of increased demand. This might include care becoming more personalised, for instance, through the provision of personal budgets or 'circles of support' initiatives. But as imperative is the need to consider the interactions between different actors involved in making decisions about support for older people – formal, semi-formal, informal and older people themselves – to consider their role in the decision-making and risk management processes, and to explore the implications for each of these taking and allocating such decisions. In particular, exploring this 'decision ecology' might include a deeper understanding of how the positive societal contributions to and from older people can be strengthened – how people and communities can be encouraged to become more kind – and how the formal social care system can better accommodate and use informal and semi-formal caring

relationships. The complexity of this arena and the myriad responsibilities of informal and semi-formal relationships, from picking up shopping to providing regular and sustained physical support to an older person (for example, helping them with mobility) has not always been helped by the imprecise language of the 'Big Society' and similar policy initiatives which fail to distinguish between the many different roles and levels of responsibility that sit within formal and non-formal care.

This discussion is taking place in a social context characterised by professionalism, risk elimination and ageism. We would argue that the framing of the former two developments is coloured by a failure to address the subtlety of the latter. When older people are a group to be managed under the same set of provisions, avoiding the 'risk' of being held accountable for quotidian hazards may be given too much weight at the expense of proper regard for the risk of compromising a particular person's integrity and autonomy. This can lead to a breakdown in trust and poor decision-making.

We have to keep this context in mind when considering that, in existing health and social care services, there has been a growth of professionalism. The specialist knowledge of professionals is respected and we expect them to take the lead in making decisions about matters where they have expertise. In turn, health and social care professionals expect the people they care for to trust their judgement. However, as discussed in this review, evidence suggests that with professionalism has come a level of risk aversion that is not always in the best interests of older people (Carr, 2010). Risk elimination has become a major concern for all professionals and service providers, and organisations have to put policies and procedures in place to reduce risk. These are designed to make them appear trustworthy, but it doesn't always have the desired effect because it can lead to cumbersome and defensive decision-making. Further, trust is often built through interpersonal contact rather than through professional experience (Smith, 2005), and decisions made on the basis of social norms, narratives, stories and networks rather than rationality (Slovic, 1999).

Building on this perspective, much literature stressed the valuable role that family, friends and other informal or semi-formal actors could play in enhancing the lives and care of older people. Although the wider community does not have a direct significant impact on decision-making in the care of older people, sports clubs, churches and informal ties to friends and family provide access to valuable social capital that is correlated to higher levels of self-worth and agency (Gray, 2009), and older people discussed how important having a neighbour who 'just pops in' could be for their wellbeing (Nocon and Pearson, 2000). Indeed, the importance of low-level community 'kindnesses' was emphasised time and again throughout the literature reviewed. A number of pertinent examples of neighbourhood or community 'kindness' schemes are captured below. Building a better understanding of these schemes and measuring their impact could be an important area for further research.

- The *Good Neighbours Service* in Kent matches volunteers to any older person in the vicinity who expresses an interest in a befriending service. Seventy per cent of referrals are from social services. The Good Neighbours Service currently has 150 service users connected to 80 volunteers. One revealing, albeit tragic, indicator of the scheme's success is the frequency of cases where the volunteer eventually agrees to be registered as the client's 'next of kin'. Another is the fact that there have already been cases where volunteers have arranged funerals for people they befriended.

- The *Free to Live* network in Leeds shows how peer networks can be used to help spread information. In 2009, a number of people in the Leeds area who were using personal budgets decided to set up a network to support others who were either already using a personal budget or considering taking it up. These services connect people who are using personal budgets so they can learn from each other's experiences (Clifton, 2011a, p. 10).
- The *Darlington Growing Old Living (GOLD)* is a group of 600-700 elderly people who volunteer to run activities and help out other older people in the community. They put on events such as tea dances, coordinate voluntary activities and act as a reference group for the council on older people's issues.
- *Circles of support* are groups of people who are invited to come together and meet regularly to offer support to someone. It is a way of sharing concerns and plans for the future with someone who needs extra help in areas of their life. The circle should include people who know and care about the person who needs support (Simpson, 2010).
- *Dawn Patrol* is an intergenerational project, run by the British Red Cross, in Newton le Willows, Merseyside. Dawn Patrol supports independence and resilience for vulnerable older people who live alone by building links with local schools. The older beneficiaries of the service display a number in their window corresponding to the appropriate day of the week to signal that all is well. The numbers are checked by young volunteers, aged between 8 and 11, on their way to school. If the right number is not shown, the school contacts the British Red Cross to set a response in motion, which starts with telephone contact (DH, 2011, p. 13).

The role of informal or semi-formal supportive relationships is complex, however. While much of the literature reviewed stressed the significance of supportive family relationships, we also found evidence that family care can be overcontrolling, risk-averse, abusive towards the older person and damaging for carers' own health (Duner and Nordstrom, 2007.). Unpaid carers can also be as risk averse as professionals and organisations. They often prefer options which reduce risk of accidents for loved ones, but which undermine a sense of control and wellbeing. This challenges assumptions that informal support is always kind, loving or preferable to formal provision and should be paid heed when expanding informal provision.

Towards the end of the process of writing this evidence review, we began to think that discussions relating to levels of acceptable risk, the nature and value of trust and attitudes to state provision are all underpinned by certain deep perceptions of value not covered in depth here. The efficacy and acceptability of major shifts in patterns of relationships and responsibilities will depend on the extent to which patterns of value shift in a concomitant and commensurate way. Our analysis of the decision ecology above would therefore be enriched by a critical examination of recent literature on how deeply held values influence our attitude to risk, change and trust (Pecorelli and Harding, 2010).

There is also a deeper question of moral psychology, recently developed in the work of Jonathan Haidt, which suggests that the perception of whether an issue is deemed ethical or procedural varies across the population. For some, looking after one's elderly relatives may be perceived as a challenge to minimise harm, and an unfortunate burden that one can legitimately expect help from the state with. For others, it is a challenge of in-group loyalty and a moral imperative that one must discharge by oneself before seeking help from others (Haidt, 2011).

Throughout this report we have also been conscious of the recurring challenge to get the ‘tone’ of the challenge right. On the one hand it is important not to assume that an ageing society is necessarily a bad thing. We need to create positive visions of older people as active agents, fully contributing not only to their own ‘care’ and that of other older people, but valued for a wider set of contributions to all generations based on, for instance, their extensive local knowledge, diverse social networks built up over a lifespan and the capacity to give time and attention to issues bigger than themselves. However, we were also conscious of the need not to sound like apologists for state withdrawal. While we have tried to present a balanced picture of informal and semi-formal care, there is a danger of implicitly framing ‘the social’ as positive and natural and ‘the state’ as artificial and imposed.

It is important to have a vision of the kind of decision ecology that might be perceived as functional, and even as optimal, without pretending that it will thereby be perfect or invulnerable to objections. Rethinking the decision ecology means connecting a myriad of complex issues from a variety of disciplines and spheres. We have tried to do that here, but are conscious that we have only scratched the surface. The challenge is that the issues are deep, broad and interconnected. Facing up to them means thinking not merely of the cognitive ‘fit’ between older people and the decisions we need them to take about their care, but also about but the ethical and political ‘fit’ between the kinds of personal and psychological qualities that seem to matter – attitudes to risk, willingness to trust, daring to be kind – for every generation. An ageing society should be a maturing society, not merely about people getting older. We hope this review will help others to make sense of how that might become possible.

NOTES

- 1 See, for instance, Department of Health, *Volunteering: Involving People and Communities in Delivering and Developing Health and Social Care Services* (2010a) and Department of Health, *A Vision for Adult Social Care: Capable Communities and Active Citizens* (2010b).
- 2 See also Richard Thaler's lecture at the RSA (www.thersa.org/events/video/archive/richard-thaler).
- 3 This figure is an adapted version of that used by Alok Asthana in his blog, 'Double Loop Learning' on the website, 'Innovators & Leaders' (<http://blog.innovatorsandleaders.com/?p=241>).
- 4 For more information see www.circlesnetwork.org.uk/index.asp?slevel=0z114z115&parent_id=115

REFERENCES

- Adams, T. (2001) 'The social construction of risk by community psychiatric nurses and family carers for people with dementia', *Health, Risk & Society*, Vol. 3, Issue 3, pp. 307–19
- Alaszewski, A. and Coxon, K. (2009) 'Uncertainty in everyday life: Risk, worry and trust.' *Health, Risk & Society*, Vol. 11, No. 3, pp. 201–7
- Alaszewski, A. and Manthorpe, J. (1998) 'Welfare agencies and risk', *Health Society and Care Community*, Vol. 6, No. 1, pp. 4–15
- Alaszewski, A., Alaszewski, H. and Harrison, L. (1998) 'Professionals, accountability and risk', in A. Alaszewski, H. Alaszewski and J. Manthorpe (eds), *Risk Health and Welfare*. Buckingham: Open University Press
- Alaszewski, A., Billings, J. and Coxon, K. (2004) 'Integrated health and social care for older persons: theoretical and conceptual issues', in Leichsenning, K. and Alaszewski, A. (eds), *Providing Integrated Health and Social Care for Older Persons: A European Overview of Issues at Stake*, Hampshire: Ashgate, pp. 53–94
- Allen, I., Hogg, D. and Peace, S. (1992) 'Elderly people in the community: Informal care', in I. Allen, D. Hogg and S. Peace (eds) *Elderly People: Choice, Participation and Satisfaction*, London: Policy Studies Institute at the University of Westminster, pp. 10–38
- Andrews, M. (2004) 'Counter-narratives and the power to oppose.' In M. Bamberg and M. Andrews (eds) *Considering Counter-narratives: Narrating, Resisting, Making Sense*. Amsterdam: John Benjamins, pp. 1–6
- Argyris, C. (1976) 'Single-loop and double-loop models in research on decision making', *Administrative Science Quarterly*, Vol. 21, No. 3, pp. 363–75
- Ariely, D. (2008) *Predictably Irrational: The Hidden Forces that Shape our Decisions*. London: HarperCollins
- Arksey, H. and Glendinning, C. (2007) 'Choice in the context of informal care-giving', *Health and Social Care in the Community*, Vol. 15, No. 2, pp. 165–75
- Ballinger, C. and Payne, S. (2002) 'The construction of the risk of falling among and by older people', *Ageing and Society*, Vol. 22, pp. 305–24
- Bamberg, M. (2005) 'Master narrative.' In D. Herman, M. Jahn and M. Ryan (eds) *Routledge Encyclopedia of Narrative Theory*. London: Routledge, pp. 113–14
- Barr, A., Stenhouse, C. and Henderson, P. (2001) *Caring Communities: A Challenge for Social Inclusion*. York: Joseph Rowntree Foundation
- Barrow, S. and Harrison, R. (2005) 'Unsung heroes who put their lives at risk? Informal caring, health and neighbourhood attachment', *Journal of Public Health*, Vol. 27, Issue 3, pp. 292–7
- Beach, S. R., Schulz, R., Williamson, G. M., Miller, L. S., Weiner, M. F. and Lance, C. E. (2005) 'Risk factors for potentially harmful informal caregiver behavior', *Behavior Journal of the American Geriatrics Society*, Vol. 53, pp. 255–61
- Beresford, P. and Andrews, E. (2012) *Caring for Our Future: What Service Users Say*. York: Joseph Rowntree Foundation

-
- Berry, L. (2011) *The Art of Living Dangerously: Risk and Regulation*. York: Joseph Rowntree Foundation
- Better Regulation Commission (2006) *Risk, Responsibility and Regulation: Whose Risk Is it Anyway?* London: Better Regulation Commission
- Bowers, H., Macadam, A., Patel, M. and Smith, C. (2006) *Making a Difference Through Volunteering: The Impact of Volunteers Who Support and Care for People at Home*. London: Age UK
- Braun, B.L. (1998) 'Knowledge and perception of fall-related risk factors and fall reduction techniques among community-dwelling elderly individuals', *Physical Therapy*, Vol. 78, pp. 1262–76
- Brindle, D. (2008) *Care and Support – A Community Responsibility?* York: Joseph Rowntree Foundation
- Brodie, E., Hughes, T., Jochum, V., Miller, S., Ockenden, N. and Warburton, D. (2011) *Pathways Through Participation: What Creates and Sustains Active Citizenship?* London: Involve, National Council for Voluntary Organisations and Institute for Volunteering Research
- Buri, H. and Dawson, P. (2000) 'Caring for a relative with dementia: A theoretical model of coping with fall risk', *Health, Risk & Society*, Vol. 2, Issue 3, pp. 283–93
- Carers UK (2011) *The Cost of Caring*. London: Carers UK
- Carr, S. (2010) *Enabling Risk, Ensuring Safety: Self-directed Support and Personal Budgets*. London: Social Care Institute for Excellence
- Carstensen, L. and Mikels, J. A. (2005) 'At the intersection of emotion and cognition aging and the positivity effect', *Current Directions in Psychological Science*, Vol. 14, No. 3, pp. 117–21
- Cherti, M. and Clifton, J. (2009) *Getting On: Wellbeing in Later Life*. London: Institute for Public Policy Research
- Chou, K. L., Lee, T. M. C. and Ho, A. H. Y. (2007) 'Does mood state change risk taking tendency in older adults?', *Journal of Psychology and Aging*, Vol. 22, No. 2, pp. 310–18
- Clarke, A., Jane Hanson, E. and Ross, H. (2003) 'Seeing the person behind the patient: enhancing the care of older people using a biographical approach', *Journal of Clinical Nursing*, Vol. 12, pp. 697–706
- Clarke, C. L. (2000) 'Risk: Constructing care and care environments in dementia', *Health, Risk & Society*, Vol. 2, No. 1, pp. 83–93
- Clemens, E. L. and Hayes, H. E. (1997) 'Assessing and balancing elder risk, safety and autonomy: Decision-making practices of health care professionals', *Home Health Care Services Quarterly*, Vol. 16, Issue 3, pp. 3–20
- Clifton, J. (2011a) *Older Londoners: Final Report*. London: Institute for Public Policy Research
- Clifton, J. (2011b) *Social Isolation Among Older Londoners*. London: Institute for Public Policy Research
- Crogan, N., Bronwynne, C. and Bendel, R. (2008) 'Storytelling intervention for patients with cancer: Part 2—Pilot testing', *Oncology Nursing Forum*, Vol. 35, No. 2, pp. 265–72
- CSJ (Centre for Social Justice) (2011) *Age of Opportunity: Transforming the Lives of Older People in the UK*. London: CSJ
- Davis, H. and Ritters, K. (2009) *Linkage Plus National Evaluation: End of Project Report, Department for Work and Pensions Research Report No. 572*, London: DWP
- Denburg, N. L., Cole, C. a, Hernandez, M., Yamada, T. H., Tranel, D., Bechara, A. and Wallace, R. B. (2007) 'The orbitofrontal cortex, real-world decision making, and normal aging', *Annals of the New York Academy of Sciences*, December
- DH (2009) *Shaping the Future of Care Together*. London: DH
- DH (2010a) *Volunteering: Involving People and Communities in Delivering and Developing Health and Social Care Services*. London: DH

- DH (2010b) *A Vision for Adult Social Care: Capable Communities and Active Citizens*. London: DH
- DH (2011) *Social Action Health and Well-being: Building Co-operative Communities – Department of Health Strategic Vision for Volunteering*. London: DH
- DH (Department of Health) and DCA (Department for Constitutional Affairs) (2005) *Mental Capacity Act 2005: A summary*. London: The Stationery Office
- Dixon, J., Manthorpe, J., Biggs, S., Mowlam, A., Tenant, R., Tinker, A. and McCreddie, C. (2010) 'Defining elder mistreatment: reflections on the United Kingdom study of abuse and neglect of older people', *Ageing & Society*, Vol. 30, pp. 403–20
- Dolan, P., Hallsworth, M., Halpern, D., King, D. and Vlaev, I. (2010) *MINDSPACE: Influencing Behaviour Through Public Policy*. London: Institute for Government
- Douglas, M. (1966) *Purity and Danger: An Analysis of Concepts of Pollution and Taboo*. London: Routledge
- Douglas, M. (1986) *Risk Acceptability According to the Social Sciences*. London: Routledge and Kegan Paul
- Dowding K. (1992) 'Choice: its increase and its value', *British Journal of Political Science*, Vol. 22, No. 3, 301–14
- Downs, M and Bowers, B. (2008) *Excellence in Dementia Care: Research into Practice*. Maidenhead: Open University Press
- Duffy, B. and Pierce, A. (2007) *Socio-political Influencers: Who Are They and Why Do They Matter?* London: Ipsos MORI
- Duner, A. and Nordstrom, M. (2007) 'The roles and functions of the informal support networks of older people who receive formal support: a Swedish qualitative study', *Ageing & Society*, Vol. 27, No. 1, pp. 67–85
- Fagerström, L., Gustafson, Y., Jakobsson, G., Johansson, S. and Vartiainen, P. (2011) 'Sense of security among people aged 65 and 75: External and inner sources of security', *Journal of Advanced Nursing*, Vol. 67, No. 6, pp. 1305–16
- Falkingham, J., Evandrou, M., McGowan, T., Bell, D. and Bowes, A. (2010) *Demographic Issues, Projections and Trends: Older People with High Support Needs in the UK*. York: Joseph Rowntree Foundation
- Faulkner, A. (2012) *The Right to Take Risks: Service Users' Views of Risk in Adult Social Care*. York: Joseph Rowntree Foundation
- Finch, J. and Mason, J. (1990) 'Filial obligations and kin support for elderly people', *Ageing and Society*, Vol. 10
- Fine, M. and Glendinning, C. (2005) 'Dependence, independence or inter-dependence? Revisiting the concepts of "care" and "dependency"', *Ageing and Society*, Vol. 25, pp. 601–21
- Finucane, M. L., Slovic, P., Hibbard, J. H., Peters, E., Mertz, C. K. and MacGregor, D. G. (2002) 'Aging and decision-making competence: an analysis of comprehension and consistency skills in older versus younger adults considering health-plan options', *Journal of Behavioral Decision Making*, Vol. 15, No. 2, pp. 141–64
- Finucane, M.L., and Satterfield, T.A. (2005) 'Risk as narrative value: a theoretical framework for facilitating the biotechnology debate', *International Journal of Biotechnology*, Vol. 7, No. 1, pp. 128–46.
- Forgas, J.P. (1994) 'Sad and guilty? Affective influences on the explanation of conflict in close relationships', *Journal of Personality and Social Psychology*, Vol. 66, pp. 56–68.
- Funk, L. M., Allan, D. E. and Stajduhar, K. I. (2009) 'Palliative family caregivers' accounts of health care experiences: The importance of "security"', *Palliative & Supportive Care*, Vol. 7, No. 4, pp. 435–47
- Furedi, F. (2011) *Changing Societal Attitudes, and Regulatory Responses, to Risk-taking in Adult Care*. York: Joseph Rowntree Foundation

- Gandhi, K. and Bowers, H. (2008) *Duty and Obligation: The Invisible Glue in Services and Support*. York: Joseph Rowntree Foundation
- Giles, L.C., Glonek, G.F., Luszcz, M.A. and Andrews, G.R. (2005) 'Effect of social networks on 10 year survival in very old Australians: the Australian longitudinal study of aging', *J Epidemiol Community Health*, Vol. 59, No. 7, pp. 574–79
- Gilleard, C. and Higgs, P. (1998) 'Ageing and the limiting conditions of the body', *Sociological Research Online*, Vol. 3, No. 4. <http://www.socresonline.org.uk/socresonline/3/4/4.html>
- Gilmour, H., Gibson, F. and Campbell, J. (2003) 'Living alone with dementia: A case-study approach to dealing with risk', *Dementia*, October, Vol. 2, pp. 403–20
- Gilson, L. (2003) 'Trust and the development of health care as a social institution', *Social Science & Medicine*, Vol. 56, Issue 7, pp. 1453–68
- Glasby, J. (2011) *Whose Risk Is It Anyway? Risk and Regulation in an Era of Personalisation*. York: Joseph Rowntree Foundation
- Glaser, B and Strauss, A. (1967) *The Discovery of Grounded Theory: Strategies for Qualitative Research*, Chicago: Aldine
- Glendinning, C. and Bell, D. (2008) *Rethinking Social Care and Support: What Can England Learn from other Countries?* York: Joseph Rowntree Foundation
- Glendinning, C., Arksey, H., Tjadens, F., Moree, M., Moran, N. and Nies, H. (2009) *Care Provision within Families and its Socio-economic Impact on Care Providers*. York: Social Policy Research Unit
- Goldberg, M. E. (2009) 'Consumer decision making and aging: A commentary from a public policy/marketing perspective', *Journal of Consumer Psychology*, Vol. 19, No. 1, pp. 28–34
- Golding, D., Krinsky, K. and Plough, A. (1992) 'Evaluating risk communication: narrative vs. technical presentations of information about radon', *Risk Analysis*, Vol. 12, No. 1, pp. 27–35.
- Grady, J. (2004) 'Working with visible evidence: an invitation and some practical advice', in Knowles, C. and Sweetman, P. (eds) *Picturing the Social Landscape: Visual Methods and the Sociological Imagination*. London: Routledge, pp. 18–31
- Graham, E. and Flowerdew, R. (2007) *Migration and the Informal Support Networks of Older People in Scotland*. St Andrews: University of St Andrews
- Gransnet (2011) Forum: 'Carers are wonderful people' (42 posts). May 2011–November 2011
- Gransnet (2011b) Forum: 'Elderly in hospital' (310 posts). May 2011–March 2012
- Gransnet (2012a) Forum: 'Loneliness is more dangerous to our health in retirement than smoking' (108 posts). March
- Gray, A. (2009) 'The social capital of older people', *Ageing & Society*, Vol. 29, No. 1, January, pp. 5–31
- Green, A., Janmaat, J. G. and Cheng, H. (2011) 'Social cohesion: Converging and diverging trends', *National Institute Economic Review*, Vol. 215, pp. 6–22
- Gutchess, A. H., Kensinger, E. a, Yoon, C. and Schacter, D. L. (2007) 'Ageing and the self-reference effect in memory', *Memory*, Vol. 15, No. 8, pp. 822–37
- Haidt, J. (2007) *The Happiness Hypothesis: Finding Modern Truth in Ancient Wisdom*. New York: Basic Books
- Haidt, J. (2012) *The Righteous Mind*. New York: Pantheon
- Hamano, T., Yamasaki, M., Fujisawa, Y., Ito, K., Nabika, T. and Shiwaku, K. (2011) 'Social capital and psychological distress of elderly in Japanese rural communities', *Stress and Health: Journal of the International Society for the Investigation of Stress*, Vol. 27, No. 2, pp. 163–9
- Harper, S. and Levin, S. (2003) *Changing Families as Societies Age: Care, Independence and Ethnicity*. Oxford: Oxford Institute of Population Ageing

- Harris, K. (2008) *Neighbouring and Older People: An Enfolding Community?* London: Age UK and Community Development Foundation
- Hayden, C., Boaz, A. and Taylor, F. (1999) *Attitudes and Aspirations of Older People: A Qualitative Study*. London: Department of Social Security
- Herring, R. and Thom, B. (1997) 'The right to take risks: Alcohol and older people', *Social Policy & Administration*, Vol. 31, pp. 213–32
- Holmes, J. (1999) 'Defensive and creative uses of narrative in psychotherapy.' In J. Holmes and G. Roberts (eds) *Healing Stories: Narrative in Psychiatry and Psychotherapy*. Oxford: Oxford University Press, pp. 49–66
- Human Resources and Skills Development Canada (2005) *Program and Policy Perspectives on the Interplay of Risk Factors and the Associated Negative Outcomes Among Family Caregivers: Key Informant Report*. Ottawa: VON Canada
- IPPR (Institute for Public Policy Research) and PwC (PricewaterhouseCoopers) (PwC) (2010) *Capable Communities: Towards Citizen-powered Public Services*. London: IPPR and PwC
- Ipsos MORI (2005) *Attitudes to Growing Older*. London: Ipsos MORI
- Ipsos MORI (2006) *General Public's High Expectations of Adult Social Care*. London: Ipsos MORI
- Ipsos MORI (2011) *Users of Social Care Personal Budgets*. London: Ipsos MORI for the National Audit Office
- Isen, A.M. (1993) 'Positive affect and decision making', in M. Lewis and J.M. Haviland (eds) *Handbook of Emotions*. New York: Guilford Press, pp. 261–77
- Johnson, M. (1995) 'Interdependency and the generational compact', *Ageing and Society*, Vol. 15, No. 2, June, pp. 243–66
- Jones, M. D. and McBeth, M. K. (2010) 'A narrative policy framework: Clear enough to be wrong?', *Policy Studies Journal*, Vol. 38, No. 2, pp. 329–53
- Kalinińska, H. H. and Shawe-Taylor, M. (2008) 'Promoting positive risk management: Evaluation of a risk management panel', *Journal of Psychiatric and Mental Health Nursing*, Vol. 15, No. 8, pp. 654–61
- Keating, N., Otfinowski, P., Wenger, C., Fast, J. and Derksen, L. (2003) 'Understanding the caring capacity of informal networks of frail seniors: A case for care networks', *Ageing and Society*, Vol. 23, No. 1, pp. 115–27
- Kemshall, H. (2002) 'Key organising principles of social welfare and the new risk-based welfare', in Kemshall, H. (ed.) *Risk, Social Policy and Welfare*. Buckingham: Open University Press
- Kirkley, C., Bamford, C., Poole, M., Arksey, H., Hughes, J. and Bond, J. (2011) 'The impact of organisational culture on the delivery of person-centred care in services providing respite care and short breaks for people with dementia', *Health & Social Care in the Community*, Vol. 19, No. 4, pp. 438–48
- Kosny, A. A. and Eakin, J. M. (2008) 'The hazards of helping: Work, mission and risk in non-profit social service organizations', *Health, Risk & Society*, Vol. 10, No. 2, pp. 149–66
- Kovalchik, S., Camerer, C. F., Grether, D. M., Plott, C. R. and Allman, J. M. (2005) 'Aging and decision making: a comparison between neurologically healthy elderly and young individuals', *Journal of Economic Behavior & Organization*, Vol. 58, No. 1, pp. 79–94
- Kraetschmer, N., Sharpe, N., Urowitz, S. and Deber, R. (2004) 'How does trust affect patient preferences for participation in decision-making?', *Health Expectations*, Vol. 7, Issue 4, pp. 317–26
- Kroode, T. (1998) 'Active listening to cancer patients' stories', *The Netherlands Journal of Medicine*, Vol. 53, No. 2, pp. 47–52
- Leight, S. B. (2002) 'Starry night: using story to inform aesthetic knowing in women's health nursing', *Journal of Advanced Nursing*, Vol. 37, pp. 108–14
- Leung, A., Kier, C., Fung, T., Fung, L. and Sproule, R. (2011) 'Searching for happiness: The importance of social capital', *Journal of Happiness Studies*, Vol. 12, No. 3, pp. 443–62

-
- Lupton, D. (1999) *Risk*. London: Routledge
- Marchant, S. (2011) *Risky Business?* York: Joseph Rowntree Foundation
- Martin, W. (2012) 'Visualizing risk: Health, gender and the ageing body', *Critical Social Policy*, Vol. 32, No. 1, pp. 51–68
- Mata, R., Schooler, L. J. and Rieskamp, J. (2007) 'The aging decision maker: Cognitive aging and the adaptive selection of decision strategies', *Psychology and Aging*, Vol. 22, No. 4, pp. 796–810
- Mitchell, W. and Glendinning, C. (2007) *Risk and Adult Social Care: What Does UK Research Evidence Tell Us?* Canterbury: University of Kent
- Mitchell, W. and Glendinning, C. (2008) 'Risk and adult social care: Identification, management and new policies. What does UK research evidence tell us?', *Health, Risk & Society*, Vol. 10, Issue 3, pp. 297–315
- Mitchell, W., Baxter, K. and Glendinning, C. (2012) *Updated Review of Research on Risk and Adult Social Care in England*. York: Joseph Rowntree Foundation
- Mittendorff, K., Geijsel, F., Hoeve, A., de Laat, M., Nieuwenhuis, L. (2006) 'Communities of practice as stimulating forces for collective learning', *Journal of Workplace Learning*, Vol. 18, No. 5, pp. 298–312
- Moody, H.R. (1993) *Ethics in an Aging Society*. Baltimore: Johns Hopkins University Press
- NatCen (National Centre for Social Research) (2012) *British Social Attitudes Survey 28th Report*. London: NatCen
- Netuveli, G., Wiggins, R., Hildon, Z., Montgomery, S. and Blane, D. (2006) 'Quality of life at older ages: Evidence from the English longitudinal study of aging (wave 1)', *Journal of Epidemiology and Community Health*, Vol. 60, No. 4, pp. 357–63
- Nocon, A. and Pearson, M. (2000) 'The roles of friends and neighbours in providing support for older people', *Ageing and Society*, Vol. 20, pp. 341–67
- Norman, A. (1980) *Rights and Risk*. London. Centre for Policy in Ageing
- Nygren, T.E., Isen, A.M., Taylor, P.J. and Dulin, J. (1996) 'The influence of positive affect on the decision rule in risk situations: focus on outcome (and especially avoidance of loss) rather than probability', *Organizational Behavior and Human Decision Processes*, Vol. 66, pp. 59–72.
- ODPM (Office of the Deputy Prime Minister) (2006) *The Social Exclusion of Older People: Evidence From the First Wave of the English Longitudinal Study of ELSA*. London: ODPM
- OPM (Office for Public Management) (2011) *Service Users' Attitudes to Risk in Using Personal Budgets*. London: OPM
- Ormerod, P. (2010) *N Squared: Public Policy and the Power of Networks*. London: RSA
- O'Sullivan, C., Mulgan, G. and Vasconcelos, D. (2010) *Innovating Better Ways of Living in Later Life*. London: The Young Foundation
- Parker, S., Spires, P., Farook, F. and Mean, M. (2008) *State of Trust: How to Build Better Relationships between Councils and the Public*. London: Demos
- Pecorelli, N. and Hardin, C. (2010) *The Big Society: Why Values Matter*. London: The Campaign Company
- Peek, M.K. and Lin, N. (1999) 'Age differences in the effects of network composition on psychological distress', *Social Science & Medicine*, Vol. 49, Issue 5, September, pp. 621–36
- Peters, E., Hess, T. M. and Va, D. (2007) 'Adult age differences in dual information processes and their influence on judgments and decisions: A review', *Perspectives on Psychological Science*, Vol. 2, pp. 1–23
- Petersen, A. and Lupton, D. (1996) *The New Public Health: Health and Self in the Age of Risk*. Thousand Oaks, CA: Sage Publications, Inc.

- Pickard, L. (2004) *Informal Care for Older People Provided by their Adult Children: Projections of Supply and Demand to 2041 in England*. London: London School of Economics and Political Science and Personal Social Services Research Unit
- Porter, E. J., Lasiter, S. and Poston, E. (2005) 'Figuring out whether they can be trusted: Older widows' intentions relative to hired non-professional home-care helpers', *Journal of Women & Aging*, Vol. 17, No. 4, pp. 77–92
- Princess Royal Trust for Carers, The (2010a) Forum: 'We can't stop mum's abuse'. August
- Princess Royal Trust for Carers, The (2010b) Forum: 'Rational decision?' July
- Princess Royal Trust for Carers, The (2011) Forum: 'Forced to care?' August 2011–November 2011
- Princess Royal Trust for Carers, The (2012) Forum: 'Am I just being selfish?'
- Ray, R. A. and Street, A. F. (2011) 'The dynamics of socio-connective trust within support networks accessed by informal caregivers', *Health*, Vol. 15, March, pp. 137–52
- Requena, F. (2010) 'Welfare systems, support networks and subjective well-being among retired persons', *Social Indicators Research*, Vol. 99, No. 3, pp. 511–29
- Ricketts, M.S. (2007) *The Use of Narratives in Safety and Health Communication*. Doctoral diss., The University of Kansas, Department of Psychology.
- Riessman, C. (1993) *Narrative Analysis*. London: Sage Publications
- Robertson, J. and Collinson, C. (2011) 'Positive risk taking: whose risk is it? An exploration in community outreach teams in adult mental health and learning disability services', *Health, Risk & Society*, Vol. 13, No. 2, April, pp. 147–64
- Rolison, J. J., Hanoch, Y. and Wood, S. (2011) 'Risky decision making in younger and older adults: The role of learning', *Psychology and Aging*, Vol. 27, No. 1, pp. 129–40
- Ross, A., Lloyd, J., Weinhardt, M. and Cheshire, H. (2008) *Living and Caring: An Investigation of the Experiences of Older Carers*, London: International Longevity Centre
- Rowson, J. (2011) *Transforming Behaviour Change: Beyond Nudge and Neuromania*. London: RSA
- Ryan, T. (2000) 'Exploring the risk management strategies of mental health service users', *Journal of Mental Health*, Vol. 11, pp. 17–25
- SCIE (Social Care Institute for Excellence) (2005) *The Health and Well-being of Young Carers*. London: SCIE
- Schwartz, B. (2004) *The Paradox of Choice: Why More Is Less*. New York: Harper Perennial
- Sen, A. (1977) 'Rational fools: a critique of the behavioural foundations of economic theory', *Philosophy and Public Affairs*, Vol. 6, No. 4, pp. 317–44.
- Simmons, A. (2000) *The Storytelling Factor: Secrets of Influence from the Art of Storytelling*. Scranton, PA: Perseus Publishing
- Simpson, B. (2010) *Practical Approaches to Safeguarding and Personalisation*. London: Department of Health
- Slovic, P. (1999) 'Trust, emotion, sex, politics, and science: Surveying the risk-assessment battlefield', *Risk Analysis*, Vol. 19, No. 4, pp. 689–701
- Smith, C. (2001) 'Trust and confidence: possibilities for social work in "high modernity"', *British Journal of Social Work*, Vol. 31, No. 2, April, pp. 287–305
- Smith, C. (2005) 'Understanding trust and confidence: Two paradigms and their significance for health and social care', *Journal of Applied Philosophy*, Vol. 22, Issue 3, pp. 299–316
- Stears, M. (2011) *Everyday Democracy: Taking Centre-Left Politics Beyond State and Market*, London: IPPR. <http://www.ipppr.org/publications/55/7993/everyday-democracy-taking-centre-left-politics-beyond-state-and-market>

-
- Sunstein, C. and Thaler, R. (2008) *Nudge: Improving Decisions About Health, Wealth and Happiness*. New Haven, CT: Yale University Press
- Tadd, W., Hillman, A., Calnan, S., Calnan, M., Bayer, T. and Read, S. (2011) *Dignity in Practice: An Exploration of the Care of Older People in Acute NHS Trusts*. Cardiff: Cardiff University
- Taylor, B. (2006) 'Risk management paradigms in health and social services for professional decision making on the long-term care of older people', *British Journal of Social Work*, Vol. 36, No. 8, pp. 1411–29
- Taylor, B. and Donnelly, M. (2006) 'Professional perspectives on decision making about the long-term care of older people', *British Journal of Social Work*, Vol. 36, No. 5, July, pp. 807–26
- Taylor, M. (2007) 'Pro-social behaviour: The future – It's up to us', Lecture
- Taylor-Gooby, P. (2002) 'Varieties of risk', *Health, Risk & Society*, Vol. 4, No. 2, pp. 109–11
- Tilse, C., Wilson, J., Roseman, J., Morrison, D. and Mccauley, A. (2011) 'Managing older people's money: Assisted and substitute decision making in residential aged-care', *Ageing and Society*, Vol. 31, No. 1, pp. 93–109
- Tomaka, J., Thompson, S. and Palacios, R. (2006) 'The relation of social isolation, loneliness, and social support to disease outcomes among the elderly', *Journal of Aging and Health*, Vol. 18, No. 3, pp. 359–84
- Vollan, B. (2011) 'The difference between kinship and friendship: (Field-) experimental evidence on trust and punishment', *Journal of Socio-Economics*, Vol. 40, No. 1, pp. 14–25
- Walker, R., Bisset, P. and Adam, J. (2007) 'Managing risk: Risk perception, trust and control in a primary care partnership', *Social Science & Medicine*, Vol. 64, No. 4, February, pp. 911–23
- Walker, A.E., Livingston, G., Cooper, C.A., Katona, C.L.E. and Kitchen, G.L. (2007) 'Caregivers' experience of risk in dementia: the LASER-AD study', *Ageing & Mental Health*, Vol. 10, No. 5, pp. 532–8
- Walters, P. and Bartlett, H. (2009) 'Growing old in a new estate: Establishing new social networks in retirement', *Ageing and Society*, Vol. 29, No. 2, February, pp. 217–36
- Warburton, J. and McLaughlin, D. (2005) 'Lots of little kindnesses: Valuing the role of older Australians as informal volunteers in the community', *Ageing and Society*, Vol. 25, pp. 715–30
- Wilson, R.S., Krueger, K.R., Arnold, S.E., Schneider, J.A., Kelly, J.F., Barnes, L.L., Yuxiao, T. and Bennett, D.A. (2007) 'Loneliness and risk of Alzheimer disease', *Arch Gen Psychiatry*, Vol. 64, No. 2, pp. 234–40
- Wilson, T. (2011) *Redirect: The Surprising New Science of Psychological change*. London: Allen Lane
- Wiseman, D. (2011) *A 'Four Nations' Perspective on Rights, Responsibilities, Risk and Regulation in Adult Social Care*. York: Joseph Rowntree Foundation
- Young, A. F., Russell, A. and Powers, J. R. (2004) 'The sense of belonging to a neighbourhood: Can it be measured and is it related to health and well being in older women?', *Social Science & Medicine*, Vol. 59, Issue 12, pp. 2627–37
- Young, H., Grundy, E. and Jitlal, M. (2006) *Characteristics of Care Providers and Care Receivers Over Time*. York: Joseph Rowntree Foundation
- Zamarian, L., Sinz, H., Bonatti, E., Gamboz, N. and Delazer, M. (2008) 'Normal aging affects decisions under ambiguity, but not decisions under risk', *Neuropsychology*, Vol. 22, No. 5, pp. 645–57

Bibliography

- Age UK (2007) *Engaged Communities and Active Citizenship*. London: Age UK
- Age UK (2008a) *Out of Sight, Out of Mind: Social Exclusion behind Closed Doors*. London: Age UK
- Age UK (2008b) *On my Doorstep: Communities and Older People*. London: Age UK

- Ahnquist, J., Wamala, S. and Lindström, M. (2010) 'What has trust in the health-care system got to do with psychological distress? Analyses from the national Swedish survey of public health', *International Journal for Quality in Health Care*, Vol. 22, Issue 4, pp. 250–8
- Alaszewski, A. (2000) 'Risk in nursing practice: Developing and sustaining trust.' In A. Alaszewski, H. Alaszewski, S. Ayer and J. Manthorpe (eds) *Managing Risk in Community Practice: Nursing, Risk and Decision Making* (pp. 1–22). London: Balliere Tindall
- Alaszewski, A. (2003) 'Risk, trust and health', *Health, Risk & Society*, Vol. 5, Issue 3
- Alaszewski, H. and Manthorpe, J. (2000) 'Finding the balance: Older people, nurses and risk', *Education and Ageing*, Vol. 15, pp. 195–209
- Alzheimer's Society (2012a) Forum: 'Moving mum to live with us.' March
- Alzheimer's Society (2012b) Forum: 'Hi, I feel shut out of my Dad's care.' April
- Alzheimer's Society (2012c) Forum: 'How do I deal with this?' April
- Amari-Vaught, E. (1999) *Trust in Family Relationships: The Elderly Person and the Female Family Caregiver*. Ipswich, MA: PsycInfo
- Anand, P. and Wailoo, A. (2000) 'Utilities versus rights to publicly provided goods: Arguments and evidence from health care rationing', *Economica*, Vol. 67, No. 268, pp. 543–77
- Andersson, E., Tritter, J. and Wilson, R. (2005) *Healthy Democracy: The Future of Involvement in Health and Social Care*. London: Involve
- Arksey, H. and Moree, M. (2008) 'Supporting working carers: Do policies in England and The Netherlands reflect "doulia rights"?' *Health and Social Care in the Community*, Vol. 16, No. 6, pp. 649–57
- Audit Commission (2009) *Financial Implications for Local Authorities of an Ageing Population: Policy and Literature Review*. London: Audit Commission
- Bamford, S. and Berry, C. (2012) *Long-term Care for Older People, Social Productivity and the 'Big Society': The Case of Dementia*. London: 2020 Public Services Hub
- Barefoot, J., Maynard, K., Beckham, J., Brummett, B., Hooker, K. and Siegler, I. (1998) 'Trust, health, and longevity', *Journal of Behavioral Medicine*, Vol. 21, No. 6, pp. 517–26
- Bartholome, C. A. and Larson, L. (1995) 'Decision making in health care: Youthful perspectives', *Bioethics Forum*, Vol. 11, Issue 4, pp. 35–7
- Beesley, L. (2006) *Informal Care in England* (Part of the Wanless Review). London: The King's Fund
- Berlin Hallrup L., Albertsson D., Bengtsson Tops A., Dahlberg K., Grahn B. (2009) 'Elderly women's experiences of living with fall risk in a fragile body: A reflective lifeworld approach', *Health & Social Care in the Community*, Vol. 17, Issue 4, pp. 379–87
- BIS (Department for Business, Innovation and Skills), DoE (Department of Energy), CLG (Department for Communities and Local Government), DWP (Department for Work and Pensions) and DH (Department of Health) (2010) *Recognised, Valued and Supported: Next Steps for the Carers Strategy*. London: The Stationery Office
- Bohnet, I. and Zeckhauser, R. (2004) 'Trust, risk and betrayal', *Journal of Economic Behavior & Organization*, Vol. 55, Issue 4, pp. 467–84
- Bornat, J. and Bytheway, B. (2010) 'Perceptions and presentations of living with everyday risk in later life', *British Journal of Social Work*, Vol. 40, No. 4, pp. 1118–34
- Bostock, L., Bairstow, S., Fish, S. and Macleod, F. (2005) *Managing Risks and Minimising Mistakes in Services to Children and Families*. London: Social Care Institute for Excellence
- Bovenberg, L., Uhlig, H., Bohn, H. and Weil, P. (2006) *Pension Systems and the Allocation of Macroeconomic Risk*. Chicago: University of Chicago Press
- Bowling, A., Barber, J., Morris, R. and Ebrahim, S. (2006) 'Do perceptions of neighbourhood environment influence health? Baseline findings from a British survey of aging', *Journal of Epidemiology and Community Health*, Vol. 60, No. 6, pp. 476–83

- Boyle, G. (2005) 'The role of autonomy in explaining mental ill-health and depression among older people in long-term care settings', *Ageing and Society*, Vol. 25, Issue 5, pp. 731–48
- Bradshaw, G., Sillett, J. and Walker, A. (2010) *Independence, Community and Environment: Final Report of the Sustainable Social Care Learning Network*. London: Social Care Institute for Excellence
- Braye, S., Orr, D. and Preston-Shoot, M. (2011) *Self-neglect and Adult Safeguarding: Findings from Research*. London: Social Care Institute for Excellence
- Browne, A. J., Hartrick Doane, G., Reimer, J., MacLeod, M. L. P. and McLellan, E. (2010) 'Public health nursing practice with "high priority" families: The significance of contextualizing "risk"', *Nursing Inquiry*, Vol. 17, Issue 1, pp. 27–38
- Calnan, M. and Rowe, R. (2007) 'Trust and health care', *Sociology Compass*, Vol. 1, Issue 1, pp. 283–308
- Cannuscio, C., Block, J. and Kawachi, I. (2003) 'Social capital and successful aging: The role of senior housing', *Annals of Internal Medicine*, Vol. 139, No. 5, Part 2, p. 395
- Carers UK (2011b) *It Could Be You: A Report on the Chances of Becoming a Carer*. London: Carers UK
- Caron, C. D., Griffith, J. and Arcand, M. (2005) 'Decision making at the end of life in dementia: How family caregivers perceive their interactions with health care providers in long-term-care settings', *Journal of Applied Gerontology*, Vol. 24, No. 3, pp. 231–47
- Carstensen, L. L., Isaacowitz, D. M. and Charles, S. T. (1999) 'Taking time seriously. A theory of socioemotional selectivity', *American Psychologist*, Vol. 54, No. 3, pp. 165–81
- Clark, H. (2006) "'It's meant that, well, I'm living a life now": Older people's experiences of direct payments.' In J. Leece and J. Bornat (eds) *Developments in Direct Payments*. Bristol: The Policy Press, pp. 79–94
- Clarke, C. L. (2009) 'Editorial: Risk and long-term conditions: The contradictions of self in society', *Health, Risk & Society*, Vol. 11, No. 4, pp. 297–302
- Clarke, C. L. and Heyman, B. (1998) 'Risk management for people with dementia.' In B. Heyman (ed.) *Risk, Health and Healthcare: A Qualitative Approach* (pp. 228–40). London: Chapman and Hall
- Clarke, C. L., Gibb, C. E., Keady, J., Luce, A., Wilkinson, H., Williams, L. and Cook, A. (2009) 'Risk management dilemmas in dementia care: An organizational survey in three UK countries', *International Journal of Older People Nursing*, Vol. 4, pp. 89–96
- Cohen, M., Halevi-Levin, S., Gagin, R. and Friedman, G. (2006) 'Development of a screening tool for identifying elderly people at risk of abuse by their caregivers', *Journal of Aging and Health*, Vol. 18, No. 5, pp. 660–85
- Conroy, S., Luxton, T., Dingwall, R., Harwood, R. and Gladman, J. (2006) 'Controversy: Cardiopulmonary resuscitation in continuing care settings: Time for a rethink?', *British Medical Journal*, Vol. 332, No. 7539, pp. 479–82
- Cooper, C., Selwood, A. and Livingston, G. (2007) 'The prevalence of elder abuse and neglect: A systematic review', *Age and Ageing*, Vol. 37, Issue 2, pp. 151–60
- Cooper, C., Walker, Z., Blizar, R. and Livingston, G. (2009) 'Abuse of people with dementia by family carers: Representative cross sectional survey', *British Medical Journal*, b155
- Croucher, K. and Lowson, K. (2011) *Handypersons Evaluation*. London: Department for Communities and Local Government
- CSJ (Centre for Social Justice) (2010) *The Forgotten Age: Understanding Poverty and Social Exclusion in Later Life*. London: CSJ
- CQC (Care Quality Commission) (2011) *The State of Health Care and Adult Social Care in England: An Overview of Key Themes in Care in 2010/11*. London: CQC
- Davis, S. and Bartlett, H. (2008) 'Healthy ageing in rural Australia: Issues and challenges', *Australasian Journal on Ageing*, Vol. 27, Issue 2, pp. 56–60

- Dawson, S., Slote Morris, Z., Erickson, W., Lister, G., Altringer, B., Garside, P. and Craig, M. (2007) *Engaging with Care: A Vision for the Health and Care Workforce for England*. London: The Nuffield Trust
- Deakin, J., Aitken, M., Robbins, T. and Sahakian, B. (2004) 'Risk taking during decision-making in normal volunteers changes with age', *Journal of the International Neuropsychological Society*, Vol. 10, pp. 590–8
- Denton, M., Zeytinoglu, I., Kusch, K. and Davies, S. (2007) 'Market-modelled home care: Impact on job satisfaction and propensity to leave', *Canadian Public Policy/Analyse de Politiques*, Vol. 33, Special Supplement on Health Human Resources, pp. S81–S99
- Derfler-Rozin, R., Pillutla, M. and Thau, S (2010) 'Social reconnection revisited: The effects of social exclusion risk on reciprocity, trust, and general risk-taking', *Organizational Behavior and Human Decision Processes*, Vol. 112, No. 2, pp. 140–50
- DH (2000) *No Secrets: Guidance on Developing and Implementing Multi-agency Policies and Procedures to Protect Vulnerable Adults from Abuse*. London: The Stationery Office
- DH (2005) *Independence, Well-being and Choice: Our Vision for the Future of Social Care for Adults in England*. London: The Stationery Office
- DH (2006) *Our Health, Our Care, Our Say: A New Direction for Community Services*. London: The Stationery Office
- DH (2007) *Putting People First: A Shared Vision and Commitment to the Transformation of Adult Social Care*. London: The Stationery Office
- DH (2008) *Health and Social Care Act 2008 (summary)*. London: The Stationery Office
- DH (2010) *Building the National Care Service*. London: The Stationery Office
- DH (2010) *Equity and Excellence: Liberating the NHS Department of Health*. London: The Stationery Office
- DH (2010) *Healthy Lives, Healthy People: Our Strategy for Public Health in England*. London: The Stationery Office
- DH (2012) *Health and Social Care Act 2012*. Press release
- Dilnot, A, Warner, N. and Williams, J. (2011) *Fairer Care Funding: the Report of the Commission on Funding of Care and Support. Volume I*. London: Commission on Funding of Care and Support
- Dong, X. and Simon, M. (2008) 'Is greater social support a protective factor against elder mistreatment?', *Gerontology*, Vol. 54, No. 6, November, pp. 381–8
- Drennan, V., Iliffe, S., Haworth, D., Tai, S.S., Lenihan, P. and Deave, T. (2005) 'The feasibility and acceptability of a specialist health and social care team for the promotion of health and independence in "at risk" older adults', *Health and Social Care in the Community*, Vol. 13, pp. 136–44
- Edlund, J. (2006) 'Trust in the capability of the welfare state and general welfare state support: Sweden 1997–2002', *Acta Sociologica*, Vol. 49, No. 4
- EHRC (Equality and Human Rights Commission) (2011) *Close to Home: An Inquiry into Older People and Human Rights in Home Care*
- Evercare (2006) *Caregivers in Decline*. Bethesda: Evercare
- Gilbert, T. (2005) 'Trust and managerialism: Exploring discourses of care', *Journal of Advanced Nursing*, Vol. 52, pp. 454–63
- Gilbert, T. and Powell, J. (2005) 'Family, caring and ageing in the United Kingdom', *Scandinavian Journal of Caring Sciences*, Vol. 19, Issue 1, pp. 53–7
- Gilson, L. (2003) 'Trust and the development of health care as a social institution', *Social Science & Medicine*, Vol. 56, Issue 7, pp. 1453–68
- GMC (General Medical Council) (2008) *Consent: Patients and Doctors Making Decisions Together. Guidelines for Doctors*. London: GMC

-
- Godfrey, M., Townsend, J. and Denby, T. (2004) *Building a Good Life for Older People in Local Communities*. York: Joseph Rowntree Foundation
- Gransnet (2012b) Forum: 'Live webchat with Paul Burstow, Minister of State for Care Services re: care in hospitals' (76 posts). February
- Gransnet (2012c) Forum: 'Old people being mistreated in their own homes' (55 posts). November 2011–March 2012
- Green, E. (2010) *Caregiver Wellness: An Inquiry of Health Risks Among Frontline Direct Caregivers of the Elderly and Disabled*. Ann Arbor: ProQuest Information & Learning
- Green, J. (2009) 'Is it time for the sociology of health to abandon "risk"?' *Health, Risk & Society*, Vol. 11, No. 6, pp. 493–508
- Habbestad, G. (2012) *The Function of Trust and Risk in Disclosure Decisions: A New Grounded Theory*. Ann Arbor: ProQuest UMI Dissertations
- Harding, E. (2007) *Towards Lifetime Neighbourhoods: Designing Sustainable Communities for All*. London: Department for Communities and Local Government
- Harris, K. (2012) 'Neighbourhood Care Groups.' Kevin Harris' blog
- Harrison, L., Alaszewski, A. and Walsh, M. (1998) 'The influence of informal relations on the management of risk.' In A. Alaszewski, L. Harrison and J. Manthorpe (eds) *Risk, Welfare and Society: Policies, Strategies and Practice*. Milton Keynes: Open University Press, pp. 64–88
- Harrison, S. and Smith, C. (2004) 'Trust and moral motivation: Redundant resources in health and social care?', *Policy & Politics*, Vol. 32, No. 3, pp. 371–86
- Heath, H. and Phair, L. (2009) 'Shifting the focus: Outcomes of care for older people', *International Journal of Older People Nursing*, Vol. 4, No. 2, pp. 142–53
- Hirst, M. (2002) 'Transitions to informal care in Great Britain during the 1990s', *Journal of Epidemiology and Community Health*, Vol. 56, No. 8, pp. 579–87
- Honkasalo, M. (2006) 'Fragilities in life and death: Engaging in uncertainty in modern society'. *Health, Risk & Society*, Vol. 8, No. 1, pp. 27–41
- Huby, G., Stewart, J., Tierney, A. and Rogers, W. (2004) 'Planning older people's discharge from acute hospital care: Linking risk management and patient participation in decision-making', *Health, Risk & Society*, Vol. 6, Issue 2, pp. 115–32
- Hudson, B., Dearey, M. and Glendinning, C. (2004) *A New Vision for Adult Social Care: Scoping Service Users' Views*. York: Social Policy Research Unit, University of York
- Humphries, R., Forder, J. and Fernández, J. (2010) *Securing Good Care for More People*. London: The King's Fund
- Hupcey, J. E. and Miller, J. (2006) 'Community dwelling adults' perception of interpersonal trust vs. trust in health care providers', *Journal of Clinical Nursing*, Vol. 15, No. 9, pp. 1132–9
- IPPR (Institute for Public Policy Research) (2009) *Expectations and Aspirations: Public Attitudes towards Social Care*. London: IPPR
- Jakobsson, U. and Hallberg, I.R. (2005) 'Loneliness, fear, and quality of life among elderly in Sweden: A gender perspective', *Aging – Clinical and Experimental Research*, Vol. 17, Issue 6, pp. 494–501
- JRF (Joseph Rowntree Foundation) (2004) *Older People Shaping Policy and Practice: Older People's Steering Group*. York: JRF
- Kendig, H., Koyana, W., Asakawa, T. and Ando, T. (1999) 'Social support of older people in Australia and Japan', *Ageing and Society*, Vol. 19, pp. 185–207
- Land, H. and Himmelwelt, S. (2010) *Who Cares: Who Pays?* London: Unison
- Law Commission (2011) *Adult Social Care Report*. London: Law Commission
- Lindström, M. (2006) 'Social capital and lack of belief in the possibility to influence one's own health: A population-based study', *Scandinavian Journal of Public Health*, Vol. 34, Issue 1, pp. 69–75

- Luxton, S. (2011) 'Carers: Experiences of risk and risk management.' In C. Logan and R. Whittington (eds) *Self-harm and Violence: Towards Best Practice in Managing Risk in Mental Health Services* (pp. 35–52), Oxford: Wiley-Blackwell
- Miller, B. and Mukherjee, S. (1999) 'Service use, caregiving mastery, and attitudes toward community services', *Journal of Applied Gerontology*, Vol. 18, No. 2, pp. 162–76
- NCVO (National Council for Voluntary Organisations) (2011) *Participation: Trends, Facts and Figures*. London: NCVO
- Nummela, O., Raivio, R. and Uutela, A. (2012) 'Trust, self-rated health and mortality: A longitudinal study among ageing people in Southern Finland', *Social Science & Medicine*, 14 March
- Nummelaa, O., Sulander, T., Rahkonen, O. and Uutelaa, A. (2009) 'The effect of trust and change in trust on self-rated health: A longitudinal study among aging people', *Archives of Gerontology and Geriatrics*, Vol. 49, Issue 3, pp. 339–42
- Orrell, M., Hancock, G. A., Liyanage, K., Woods, B., Challis, D. and Hoe, J. (2008) 'The needs of people with dementia in care homes: The perspectives of users, staff and family caregivers', *International Psychogeriatrics*, Vol. 20, No. 5, pp. 941–51
- Parston, G. and Kippin, H. (2010) *Improving Health Outcomes: A Guide for Action*. London: 2020 Public Services Trust
- Pearce, M. (2005) 'A critical review of the forms and value of religious coping among informal caregivers', *Journal of Religion and Health*, Vol. 44, No. 1, pp. 81–118
- Pelligra, V. (2011) 'Empathy, guilt-aversion, and patterns of reciprocity', *Journal of Neuroscience, Psychology and Economics*, Vol. 4, No. 3, pp. 161–73
- Persson, L. and Rydén, A. (2006) 'Themes of effective coping in physical disability: An interview study of 26 persons who have learnt to live with their disability', *Scandinavian Journal of Caring Sciences*, Vol. 20, No. 3, pp. 355–63
- Pickard, L. (2011) 'Substitution between formal and informal care: A "natural experiment" in social policy in Britain between 1985 and 2000', *Ageing and Society*, Vol. 32, Issue 7, pp. 1147–75
- Powell, J. (2008) *Aging and Social Welfare: The Case of Trust and Risk*. Sincronia. Accessed online at <http://sincronia.cucsh.udg.mx/powellfall08.htm>
- Powell, J. (2009) 'From "trust society" to the "risk society"? The case of aging and welfare in Europe', *Hallym International Journal of Aging*, Vol. 11, Issue 1, pp. 65–76
- Powell, J. (2011) 'Towards a sociology of trust: Community care and managing diversity', *Sociology Mind*, Vol. 1, No. 2, pp. 27–32
- Powell, J. and Owen, T. (2006) "'Trust", professional power and social theory: Lessons from a post-Foucauldian framework', *The International Journal of Sociology and Social Policy*, Vol. 26, No. 3/4, pp. 110–20
- Powell, J., Wahidin, A. and Zinn, J. (2006) 'Understanding risk and old age in western society', *International Journal of Sociology and Social Policy*, Vol. 27, Issue 1/2, pp. 65–76
- Powell, J., Wahidin, A. and Zinn, J. (2007) 'Understanding risk and old age in western society', *The International Journal of Sociology and Social Policy*, Vol. 27, No. 1/2, pp. 65–76
- Princess Royal Trust for Carers, The (2010c) Forum: 'Anyone been accused of benefit fraud relating to carers allowance?' August
- Princess Royal Trust for Carers, The (2010d) Forum: 'No protection for paid carers?' February
- Princess Royal Trust for Carers, The (2012b) Forum: 'I am fed up with coping with this on my own...' April
- Princess Royal Trust for Carers, The (2012c) Forum: 'Am I a carer?' February
- Ramsden, S. (2010) *Practical Approaches to Co-production: Building Effective Partnerships with People Using Services, Carers, Families and Citizens*. London: Department of Health
- RAND Europe (2012) *National Evaluation of the Department of Health's Integrated Care Pilots*. London: Department of Health and Ernst & Young

- Rankin, J. and Regan, S. (2002) *Meeting Complex Needs: The Future of Social Care*. London: IPPR and Turning Point
- Reay, A. and Browne, K. D. (2011) 'Risk factor characteristics in carers who physically abuse or neglect their elderly dependants', *Aging & Mental Health*, Vol. 5, No. 1, pp. 56–62
- Robinson, L., Hutchings, D., Corner, L., Finch, T., Hughes, J., Brittain, K. and Bond, J. (2007) 'Balancing rights and risks: Conflicting perspectives in the management of wandering in dementia', *Health, Risk & Society*, Vol. 9, No. 4, pp. 389–406
- Roe, B., Howell, F., Riniotis, K., Beech, R., Crome, P. and Ong, B. N. (2009) 'Older people and falls: Health status, quality of life, lifestyle, care networks, prevention and views on service use following a recent fall', *Journal of Clinical Nursing*, Vol. 18, Issue 16, pp. 2261–72
- Rossotti, N. G., Winter, D. A. and Watts, M. H. (2006) *Personal Construct Psychology: New Ideas*. Hoboken, NJ: John Wiley & Sons
- Ryan, A. A. and Scullion, H. F. (2000) 'Family and staff perceptions of the role of families in nursing homes', *Journal of Advanced Nursing*, Vol. 32, Issue 3, pp. 626–34
- Schapira, M., Nattinger, A. and McHorney, C. (2007) 'Frequency or probability? A qualitative study of risk communication formats used in health care', *Medical Decision Making*, Vol. 21, No. 6, pp. 459–67
- Simpson, B. and Murray-Neill, R. (2010) *Carers and Personalisation: Improving Outcomes*. London: Department of Health
- Smith, C. (2001) 'Trust and confidence: Possibilities for social work in "high modernity"', *British Journal of Social Work*, Vol. 31, No. 2, pp. 287–305
- Smith, C. (2005) 'Understanding trust and confidence: Two paradigms and their significance for health and social care', *Journal of Applied Philosophy*, Vol. 22, Issue 3, pp. 299–316
- Smith Wagner, L. and Wagner, T. (2003) 'The effect of age on the use of health and self-care information: Confronting the stereotype', *The Gerontologist*, Vol. 43, No. 3, June, pp. 318–24
- Stevenson, O. (1999) 'Old people at risk.' In P. Parsloe (ed.) *Risk Assessment in Social Care and Social Work* (pp. 201–16). London: Jessica Kingsley Publishers
- Tanner, D. (2003) 'Older people and access to care', *British Journal of Social Work*, Vol. 33, No. 4, June, p. 499
- Taylor, B. J. (2006) 'Risk management paradigms in health and social services for professional decision making on the long-term care of older people', *British Journal of Social Work*, Vol. 36, No. 8, pp. 1411–29
- Taylor, B. J. and Donnelly, M. (2006) 'Risks to home care workers: Professional perspectives', *Health, Risk & Society*, Vol. 8, No. 3, pp. 239–56
- Taylor-Gooby, P. (ed.) (2000) *Risk Trust and Welfare*. New York: St Martin's Press, in association with 'Economic Beliefs and Behaviour', an Economic and Social Research Council Research Programme
- Taylor-Gooby, P. (2006) 'Trust, risk and health care reform', *Health, Risk & Society*, Vol. 8, No. 2, June, pp. 97–103
- Taylor-Gooby, P. and Zinn, J. (eds) (2006). *Risk in Social Science*. Oxford: Oxford University Press
- Telford, R. and Rogers, A. (2002) 'What influences elderly people's decisions about whether to accept the influenza vaccination? A qualitative study', *Health Education Research*, Vol. 18, No. 6, pp. 743–53
- Think Local, Act Personal Partnership (2011) *Think Local, Act Personal: A Sector-wide Commitment to Moving Forward with Personalisation and Community-based Support*. London: Think Local, Act Personal Partnership
- Tinker, A. (1997) 'The environment of ageing', *Philosophical Transactions: Biological Sciences*, Vol. 352, No. 1363, pp. 1861–9
- Triantafillou, J. et al. (2010) *Informal Care in the Long-term Care System: European Overview Paper*. Athens/Vienna: Interlinks

-
- Vanlaere, L., Bouckaert, F. and Gastmans, C. (2007) 'Care for suicidal older people: Current clinical-ethical considerations', *Journal of Medical Ethics*, Vol. 33, No. 7, pp. 376–81
- Wagner, L. (2003) 'The effect of age on the use of health and self-care information: Confronting the stereotype', *The Gerontologist*, Vol. 43, No. 3, June, pp. 318–24
- Walker, A. E., Livingston, G., Cooper, C. A., Katona, C. L. E. and Kitchen, G. L. (2006) 'Caregivers' experience of risk in dementia: The LASER-AD Study', *Aging & Mental Health*, Vol. 10, Issue 5, pp. 532–8
- Walls, J., Pidgeon, N., Weyman, A. and Horlick-Jones, T. (2004) 'Critical trust: Understanding lay perceptions of health and safety risk regulation', *Health, Risk & Society*, Vol. 6, Issue 2, June, pp. 133–50
- Wanless, D. and Forder, J. (2006) *Securing Good Care for Older People (The Wanless Review)*. London: King's Fund
- Ward, P. and Meyer, S. (2009) 'Trust, social quality and wellbeing: A sociological exegesis', *Development and Society*, Vol. 38, No. 2, pp. 339–63
- Ware, T., Matosevic, T., Hardy, B., Knapp, M. and Kendall, J. (2003) 'Commissioning care services for older people in England: The view from care managers, users and carers', *Ageing and Society*, Vol. 23, No. 4, July, pp. 411–28
- Waugh, F. (2009) 'Where does risk feature in community care practice with older people with dementia who live alone?', *Dementia*, Vol. 8, No. 2, pp. 205–22
- Webb, S. (2006) *Social Work in a Risk Society: Social and Political Perspectives*. London: Palgrave Macmillan
- Wilkie, R., Peat, G., Thomas, E. and Croft, P. (2006) 'The prevalence of person-perceived participation restriction in community-dwelling older adults', *Quality of Life Research*, Vol. 15, No. 9, pp. 1471–9
- Wilson, G. (1994) 'Co-production and self-care: New approaches to managing community care services for older people', *Social Policy & Administration*, Vol. 28, Issue 3, pp. 236–50
- Wilson, S., Morse, J. M. and Penrod, J. (1998) 'Developing reciprocal trust in the caregiving relationship', *Qualitative Health Research*, Vol. 8, No. 4, pp. 446–65
- Wilton, C. and Routledge, M. (2010) *Practical Approaches to Improving the Lives of Disabled and Older People through Building Stronger Communities*. London: Department of Health
- Wright, F. (2000) 'The role of family care-givers for an older person resident in a care home', *British Journal of Social Work*, Vol. 30, No. 5, October, p. 649
- Xie, H., Chausalet, T. J., Thompson, W. A. and Millard, P. H. (2007) 'A simple graphical decision aid for the placement of elderly people in long-term care', *The Journal of the Operational Research Society*, Vol. 58, No. 4
- Zinn, J. (2009) 'The sociology of risk and uncertainty: A response to Judith Green's "Is it time for the sociology of health to abandon "risk"?"', *Health, Risk & Society*, Vol. 11, No. 6, pp. 509–26

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