

Risk and Adult Social Care: What Does UK Research Evidence Tell Us?

Abstract

Risk is a central defining feature and area of concern in adult social care provision, but what do we actually know? This question is increasingly important; as current policy advocates greater service user choice and control through a range of self-directed support mechanisms, and statutory duties and professional boundaries are challenged. This paper reports the results of a recently completed UK based scoping review and demonstrates how different groups of adult social care service users and service providers view and seek to rationalise the everyday risks they face very differently. It also shows how different management strategies are adopted, premised on different priorities and concerns, which can lead to tensions and potential conflict. However, whilst some areas of risk in adult social care have been the focus of considerable research, others have been largely ignored. The voices of some groups of users remain hidden and apparently of little concern. These gaps and inconsistencies will be identified and discussed in relation to current policy developments, and wider implications are also raised.

1. Introduction

The concept of 'risk', its relevance and effect (both potential and actual) on individuals and groups' lives in terms of their behaviour and outlook has become increasingly important and much debated in late modern society. Risk is complex and multi-dimensional, definitions and perceptions can vary across and within societies and/or cultures and, are frequently historically and event specific. Indeed, there is a growing body of literature within many academic disciplines exploring perceptions of risk: what is 'risk' and 'risky behaviour' and how this is managed in everyday life. Risk has also gained credence and prominence in the area of policy and practice, especially social policy. This growth has mirrored an increasing emphasis on personalisation and choice in the welfare state in general and social care in particular. This has been demonstrated in the recent flurry of policy guidance and discussion, such as *Risk, Responsibility and Regulation* (Better Regulation Commission, 2006), *Making Choices: Taking Risks* (Commission for Social Care Inspection, 2006) and the *Risk and Choice Framework* (Department of Health, 2007).

However, it is important to recognise that the field of adult social care is large and disparate; there are many different perspectives to consider, including those of service providers, of potential and actual service users and their carers. Moreover, perceptions of risk and views on what might constitute acceptable practice in appraising and assessing potential risks are likely to differ between different groups of professionals and the support they provide to different groups of service users and informal carers in areas such as, mental health, disability and older age. Beyond this, there is also the population at large to consider who may have normative views of risk and concerns about the potential consequences of risky behaviour that service users may undertake, especially in areas such as mental health. The role of the media in shaping and, one could argue, amplifying some of these perspectives must also be acknowledged.

This paper reports and discusses the results of a recently completed scoping review of the UK evidence base on perceptions of risk and risk management in adult social care. The paper is divided into five sections. The first section provides a brief overview of risk in relation to recent UK policy developments. The second section presents the scoping review, its aims, methods and characteristics. The third and fourth sections summarise the evidence base, highlighting a number of gaps in the literature and suggestions for future research. The paper concludes with a discussion of key themes and policy issues.

Background

As noted above, the concept of 'risk' is complex; this is reflected in the many competing theoretical ideas and approaches to risk and the idea that we are moving

to a 'risk' dominated society in late modernity (Beck, 1992; Giddens, 1991). Lupton (1999) suggests that there are two very broad approaches: '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. Ideas of 'being scientific' and developing or establishing a degree of accuracy are central, risk is viewed as largely objective, risk factors can be identified (especially by 'experts' and their 'expert' knowledge) and measured with the use of assessment tools. Despite the many different approaches, there is a recurring belief that risk can be measured independently of socio-cultural ideas and practices. Hence, lay knowledge and individual actors' perceptions of risk and its management frequently receive less attention. In contrast, although socio-cultural approaches may recognise that risk can sometimes be experienced and/or viewed objectively; greater importance is given, as Lupton (1999) notes, to social, cultural and/or economic structures, processes and interpretations (see also Douglas' work, 1992). How risk is identified and viewed is context bound, there is a shared understanding of the importance of human reflexivity and subjectivity, hence, the need to take account of lay knowledge and ideas (see Wynne, 1996).

In western society, 'risk' is frequently viewed negatively; consequently it is believed that the state in general and welfare professionals in particular have a responsibility to provide appropriate safeguards and avoid potential harm to both the public and individuals, particularly vulnerable people (Titterton, 2005; Alaszewski *et al.*, 2004). Historically, this was clearly demonstrated via, the institutionalisation of individuals perceived as 'dangerous' in need of protection, either physically, socially or morally (for example, the mentally ill). Professional knowledge and judgement was largely accepted and trusted. More recently the ethos and practice underpinning social welfare policies has shifted away from institutional to community based care. For both economic and ethical reasons it is now accepted that the most frail and vulnerable people should live outside institutional settings, as should all but the most 'dangerous'. This development has been accompanied by a more positive view of risk as a potential learning experience, underpinned by wider late modernity ideas of reflexivity (Giddens, 1991) and the importance of individual choice.

However, it has also brought to the fore many contradictions and potential tensions surrounding risk and social care. For example, in social policy, there is a growing interest in risk taking, and assessing carefully, the benefits and dangers of risks (Alaszewski *et al.*, 2004). This has become increasingly pertinent as policy advocates greater service user choice and control in an increasing range of social care settings and for more diverse groups of service users, such as self-directed support mechanisms, especially direct payments, In Control and individual budgets. These developments mirror broader policy trends, as noted by Taylor-Gooby's (2006) focus on decentralized budgets, the allocation or assignation of resources to individuals and an expanded range of service providers (mixing private, voluntary and informal). These developments reflect a transfer of power and responsibility for

managing risk. One can also argue that this reflects declining levels of 'trust' in professionals and their knowledge (Beck, 1992; Giddens, 1991). However, as Taylor-Gooby (2006), Horlick-Jones (2004) and Webb (2002) highlight, this decline, especially trust in 'expert' knowledge and practice, is multi-dimensional and the degree and importance of 'trust' attached to 'experts' amongst the lay population is much debated. Taylor-Gooby (2006) suggests that 'trust' is based on both 'rational/cognitive' knowledge and also 'non-rational/affective' ideas and lay experiences. Both are relevant to understanding how individual actors understand and react to risk but for Taylor-Gooby, welfare policy and policy makers frequently take little account of the latter. Hence, risk policies/practices may appear irrelevant or misguided to some members of the public.

The current policy focus in adult social care on 'choice', 'responsibility' and 'empowerment' also highlights (see Kemshall, 2002; Lupton, 1999; Kemshall, 1997) a number of tensions surrounding risk and adult social care. As noted above, statutory duties and professional boundaries are being redefined and challenged. However, professionals still retain responsibilities to clients and to the wider society, and issues of control remain for the state with the belief that risk needs to be managed. Tensions centre on welfare agencies and practitioners' 'duty of care' to protect 'vulnerable' individuals, alongside the growing importance assigned to individual autonomy. Balancing service user risk taking, rights, autonomy and empowerment with issues of protection in, as Kemshall (2002) notes, a context of limited resources, increasing public scrutiny and fear of professional litigation is complex. In addition, some theorists highlight an increasing emphasis on each individual's responsibility to assess and manage risk in their own life (Lupton, 1999; Foucault, 1988). The implications of these tensions are complex and potentially far reaching and, as Titterton (2005) suggests, only just beginning to be discussed and explored in the field of social care.

The importance of risk in social welfare, particularly adult social care has recently been addressed in the government's Green Paper, *Independence, Well-being and Choice* (2005). This paper called for more information and debate about risk assessment and management in adult social care for practitioners. An attempt to balance the protection of vulnerable adults, as documented in the '*No Secrets*' guidance (DoH, 2000) with policies that encourage and facilitate service users to take greater control of their lives, (including opportunities to take and manage risks), a '*Risk and Choice*' framework has been produced. This framework (DoH, 2007) establishes both risk assessment and management guidance and a range of assessment tools to help and guide practitioners and professionals working predominately in the field of adult social care.

Risk management in adult social care is thus an emerging and often uncharted area for different groups of people. Recognising this, the paper reports the results of a recently completed scoping review and provides an overview of our current

knowledge on risk. It highlights key gaps in our knowledge of the evidence base and explores a plurality of views of risk and its management (service users, carers and practitioners). The paper demonstrates the importance of different subjective ideas, documents areas of key tension and how these are managed in everyday life and practice.

2. Scoping Review: Aims, methods and characteristics

The review had two key objectives:

- To review the research evidence on the perceptions and management of risk within and between different groups of adult social care service users and professional staff.
- To identify significant gaps in evidence on the perceptions and management of risk within and between different groups of service users practitioners.

As a scoping rather than systematic review (Arksey and O'Malley, 2005), clear inclusion/exclusion parameters were set. Recent data from 1990 onwards, primarily empirically based UK research; especially research carried out in England was reviewed. Due to time and resource limitations grey and unpublished literature was not included. The review focused on perceptions of risk and their negotiation and management in adult social care, including services provided by public, private, formal/voluntary and informal sectors and also different forms of user-directed support. The review included a range of service users such as, older people, disabled people, young people moving from child to adult services, members of black and minority ethnic communities, drug and alcohol service users and informal carers. The review excluded acutely mentally ill people and services for them. Clinically or predominately health care based research was also excluded; however, research involving intermediate care, hospital to home or residential settings was included. Literature from a range of disciplines was also searched.

Methods and scope of the evidence base

The researchers developed and piloted a list of key search terms; these were divided into three areas: client group, setting and dimensions of risk. Seven databases and four relevant websites were searched, 31 academic and risk researchers were consulted and a small number of key journals were hand searched. Initial searches generated a large number of potential references (1,430); however, after a two stage process involving both researchers, to exclude references that did not meet the study's criteria (as noted above), 239 references were retrieved. The lead researcher read their abstracts and made a final decision, 151 references were ultimately included in this review. These were all read (in the vast majority of cases the full article/chapter) and relevant information from each reference was entered

onto an access database (see Mitchell and Glendinning, 2007 for more details of methods).

Tables 1 to 4 outline the scope of the literature selected for inclusion in terms of the type of literature identified, the research approach taken and the research focus, both areas of adult social care researched/discussed and the perspective taken.

References were categorised into four broad types:

- Original empirical research
- Literature reviews - predominately empirical research
- Scholarly discussion pieces - usually combining a literature review with the author's own thoughts/suggestions and/or past empirical research
- Unpublished but publicly available project reports.

Table 1 Type of literature identified (n=151)

<i>Type</i>	<i>Number of references</i>
Original empirical	92
Literature review	14
Scholarly discussion	43
Project reports	2
Total	151

Table 1 highlights that over 60 per cent of the literature reviewed (both original empirical and project reports) focused on specific empirical studies.

Table 2 Areas of service user research (n=151)

<i>Area</i>	<i>Number of studies</i>
Older people	46
Disability	22
Mental health	19
Young people moving to adult services	12
Black and minority ethnic people	3
Substance misuse	3
Younger adults with dementia	2
General overview of numerous areas*	44
Total	151

* General overviews usually focused on older people, learning disabilities and mental health

Table 2 demonstrates that the evidence base was unevenly balanced, almost a third of the literature concentrated specifically on older people and 20 out of the 22 disability related studies, focused on adults with learning disabilities. Overall, risk and older people, adults with learning disabilities and adults with mental health issues were the three key areas discussed (although only 19 studies specifically focused on mental health, this was frequently discussed in general overviews), substantially less research was found on young people in transition to adult services, black and ethnic minority people, people who misuse substances and younger adults with dementia.

Table 3 The balance of User, Informal Carer and Practitioner perspectives within original empirical references* (n=94)

<i>Perspective</i>	<i>Number of references</i>
Service users	5
Service users and carers	10
Service users and practitioners	20
Service users, carers and practitioners	16
Carers	2
Carers and practitioners	8
Practitioners	32
Total	93**

* References categorised as 'original empirical' and 'project reports'.

** One study focused on evaluating media outputs and so has not been included in this table.

The balance of perspectives explored in the empirically based studies was similarly unequal (Table 3). A third of studies (32) focused on practitioner/staff views, only a very small number concentrated solely on the views of service users or carers. Service user views were more frequently presented (35 studies in total) when they complemented or contested those of practitioners or informal carers.

Original empirical research was broadly classified as qualitative, quantitative or mixed methods (qualitative and quantitative).

Table 4 General research approach employed by empirical research* (n=94)

<i>Research approach</i>	<i>Number of references</i>
Qualitative	80
Quantitative	2
Mixed – qualitative and quantitative	12
Total	94

* References categorised as 'original empirical' or 'project reports'.

Table 4 highlights that the vast majority of studies were qualitatively based (80); very few studies were solely quantitative (2). Within the qualitative studies, four were pilot project evaluations and nine described themselves as case studies.

3. Overview of the evidence base

This section presents an overview of the evidence base and summarises some of the key themes and issues that have emerged. As noted previously, a large number of references (151) were included in the research, however, only 94 of these were actually empirically based studies and within this, some of the references discussed the same study. Furthermore, many of the 57 literature reviews and scholarly discussions identified reviewed these empirical studies and hence, addressed similar issues. The actual evidence base that currently exists is thus smaller and more limited than the number of identified references initially suggests. Recognising this and the practical limitations of trying to summarise a substantial amount of data, this section focuses only on references identified and categorised as empirical (see Mitchell and Glendinning, 2007 for a more in-depth review of the evidence base).

Mental health

'Risk and danger', especially, the idea that mental health service users are a danger to others was the main focus of studies exploring risk and mental health (see Warner, 2006; Goodin, 2004; Kelly and McKenna, 2004; Warner and Gabe, 2004; Langan and Lindow, 2000). Amongst these studies, the ideas, experiences and practices of mental health service staff and practitioners were frequently explored, in particular, practitioners' perceptions of mental health users as 'dangerous'. Studies examined 'how' practitioners assess degree or degrees of 'danger'; the presumptions and/or social ideas that their views and assessments are based on; and the resulting risk management strategies that they employ.

Research identified was frequently grounded or explored in relation to the wider socio-economic context within which practitioners work and live. Authors contextualised their research against the background of previous official inquiries and media scares involving mental health service users and the dangers they have posed to society, in particular, physical ‘harm’ encountered by individuals, especially ‘innocent’ members of the public (e.g. Warner, 2006). Much of the research identified considered how this wider social context of fear and blame, especially concerns surrounding litigation (whether real or apocryphal) was recognised by practitioners and the effects that this can have on their everyday practice of defining and managing risk. Indeed, a number of studies, especially the work of Alaszewski and colleagues (Alaszewski *et al.*, 1998, 1999; Alaszewski and Manthorpe, 1998), has demonstrated that practitioners from different areas of social care (mental health, older people and learning disabilities) can view risk differently, with mental health service practitioners more likely to focus on risk as ‘danger’, compared to colleagues in other areas of social care. In addition, the literature also suggested that ‘dangerousness’, race and ethnicity were interwoven, largely premised on biological and cultural presumptions of ‘difference’ (Warner, 2006; Warner and Gabe, 2004; Langan and Lindow, 2000; Browne, 1995).

There was an absence of research exploring the views of mental health service users, especially users’ own experiences of the risks that their illness can bring for them on a personal, everyday level. This may include the risk of self-harm or personal injury, social isolation and stigma in the community within which they live; increased surveillance from others (especially mental health practitioners); and negative effects of medication. These issues were highlighted by service users in only a very small number of empirical studies (Kelly and McKenna, 2004; Ryan, 2000; Alaszewski *et al.*, 1998); the authors themselves noted this as an area receiving little attention.

Although one of the two studies focusing solely on the voice of informal carers was in the field of mental health (see Table 3, Section 2), in general, there were very few studies exploring the ideas and experiences of risk and its management from a carers’ perspective. One exception was Ryan’s (2002) study. This seemed to stand in contrast to research in other areas, especially older people and adults with learning disabilities where the views of carers were explored, albeit, usually alongside practitioners’.

Older people

The majority of studies of risk and older people (see especially the work of Clark *et al.*, 1998, 1996a, 1996b; Clarke, 2000, 1999; Buri and Dawson, 2000) focused on the everyday risks older people can encounter when they return or seek to remain living in their own home. In general, the main area of concern focused on physical risks; for example, falling or physically harming oneself as a result of doing ‘risky’ actions in

areas such as, housework, cooking and personal hygiene, especially bathing or showering. There appeared to be less research and concern on the risks of damage to psychological well-being that service users and their carers could face. The other main area of research evidence was the process of risk assessment during hospital discharge. This usually involved assessment of risk in relation to older people returning home and explored how risk was assessed by different parties (especially service users and practitioners) and the level of assessment participation experienced by different participants (particularly the older person being assessed). This research (especially the work of Huby *et al.*, 2004) examined if the older people being assessed had wanted to be involved in the process and, if they felt that practitioners had involved them. Barriers excluding older people's inclusion were discussed, both in terms of practitioner ideas/presumptions and also organisational practices and/or structures.

Overall, the evidence base in this review with regard to older people identified a range of perspectives and experiences. The views of staff and practitioners from both social care and health care were explored; indeed, the literature compared the views and practices of different practitioners across social and health care settings and agencies, for example, the views of hospital occupational therapists and community based social workers. Three key studies (Alaszewski *et al.*, 1998; Alaszewski and Manthorpe, 1998; Alaszewski *et al.*, 1999) exploring and comparing practitioners views (especially nurses) across social care (older people, learning disability and mental health) demonstrated that how risk was viewed and the management strategies prioritised frequently reflected wider professional ethos' and priorities. Similarly, the organisational context was also important (i.e. procedures and practices) and length and type of experience. In addition, the views of practitioners and managers within the same area of social care were also compared and areas of potential conflict noted, for example, the level of support available to individual clients and their families.

Research exploring carers' risk management strategies highlighted the importance of placing each carer's personal ideas of 'what is risky' behaviour in the context of the subjective meanings they personally attach to their caring role and their past relationship with the older person currently supported. Studies (especially Clarke's research: Clarke, 2000; Clarke and Heyman, 1998) presented this as an active process carers engage in, what is 'risky' behaviour and 'how' or even 'whether' to manage potential risk is constantly being negotiated and re-negotiated by the carer and older person, as circumstances or priorities change. This process of 'normalisation' was shown to be dynamic and ongoing rather than static.

How older people viewed and personally assessed the risks they faced in their everyday lives was also considered. Research demonstrated that this was often a complex and lengthy process for older people involving issues of personal choice and retaining a degree of independence and control. Studies (such as Wilson, 1994)

indicated that for many older people, deciding 'what is risky?' and whether to take a risk was often a multi-dimensional process weighing up potential costs and benefits. It was apparent that for a number of older participants, some risk taking behaviour was felt to be worth 'taking a risk' for as, the perceived personal benefits, especially psychological benefits, were felt to outweigh potential negative dangers or consequences. Hence, the importance of older people taking risk actions covertly, unbeknown to their informal or paid carers (see Clark *et al.*, 1996a, 1996b) was identified.

What is regarded as 'risky behaviour' and whether a risk is worth taking emerged as a general theme, however, it was viewed differently by service users, their carers and practitioners. Research also highlighted the need for practitioners to listen to older people and their informal carers, to recognise and value the importance of subjective interpretations of risk and when assessing and planning management strategies to place these in the wider socio-economic context of each service user and their family's personal life (Buri and Dawson, 2000; Wilson, 1994).

In addition, the importance of psychological well-being has also been identified, especially with regard to older people and the importance of retaining a degree of personal independence and control (see Clark *et al.*'s. 1998, 1996a, 1996b; and Wilson's, 1994 research). However, as noted above, the importance of risk and damage to psychological well-being appeared to be less well-researched.

Disabled adults

As noted in section 2, research specifically on disabled people focused on adults with learning disabilities (20 out of 22 references). The two studies drawing on wider samples of disabled people included those with physical impairments. A slightly broader focus was found in studies exploring young people and the transition from child to adult services, here, seven out of nine studies included young people with physical or multiple impairments.

Much of the evidence was grounded in the theoretical framework of normalisation and its guiding principles, i.e. the importance of people with learning disabilities living as normal a life as possible (see Wolfensberger, 1972; O'Brien, 1992). Inherent within this, it is recognised that taking risks is part and parcel of everyday life and can be a positive personal learning experience for people with learning disabilities. Many of the studies identified, highlighted the importance of normalisation, in particular, they explored how normalisation theory was both recognised by practitioners working with people with learning disabilities and could guide the degree of risk taking they advocated. Evidence comparing practitioners in different areas of social care, once again, found that different professional ethos' and practices were important between different groups of practitioners, those working with adults with learning disabilities

were more likely to view risk positively and part of everyday life compared to colleagues in other areas of social care (see the work of Alaszewski *et al.*, 1998, 1999).

Research identified examined the ideas of all parties; service users, carers (usually parents) and staff/practitioners. However, the views of carers/parents were often reported in more detail than those of people with learning disabilities (i.e. their son/daughter). Reporting the views of adults with learning disabilities, studies (see particularly the work of Heyman and Huckle, 1993a, 1993b, 1995; Alaszewski *et al.*, 1998, 1999) demonstrated that adults with learning disabilities' perception of risk and 'what is risky' behaviour and thus dangerous for them, frequently mirrored their parents/carers views on risk and danger. Only a very small number of studies (e.g. McConkey and Smyth, 2003) have explored and found differences of opinion between people with learning disabilities and their parents. There also appears to be less research on how people with learning disabilities actually manage risk, the research focus is largely on their perceptions of what is 'risky' and dangerous.

Generally, the focus on 'risk' for people with learning disabilities concentrated on risk taking in the context of everyday life, especially participating in 'normal' community life such as, independent travel, shopping or socialising with others, including members of the opposite sex. There was very little, if any discussion of risk and homosexual relationships for people with learning disabilities. Fears surrounding sexuality and the dangers this was felt to pose for those with learning disabilities were a common theme and area of interest. Research explored both the fear that people with learning disabilities were vulnerable to sexual abuse, i.e. they were often 'victims' (see Heyman and Huckle, 1993a, 1993b, 1995 and Banim *et al.*'s, 1999 work), and also, their role as perpetrators of sexual abuse. However, this latter issue appears to have received less research attention compared to that of adults with learning disabilities as 'victims' of abuse. Only a very small number of studies (Thomson, 2000; Brown *et al.*, 1994) have explored practitioners' views of, and concerns surrounding service users as potential abusers.

Studies exploring carers/parents risk ideas and experiences have focused on their fear of risk and reluctance to actively encourage risk taking behaviour. Research indicates that parents adopt different degrees of risk management depending on how they view the danger attached to everyday activities. Once again, what is risky behaviour is based on subjective ideas and personal experiences. Some parents (see Heyman and Huckle, 1993a, 1993b, 1995) try to manage risk (recognising that some degree of risk taking is necessary) whereas, other parents seek to avoid risk taking 'at all cost'. As noted above with older people, risk is viewed differently by different parties; by adults with learning disabilities, practitioners, informal carers/parents, and also between parents themselves.

People who misuse substances, black and ethnic minorities and young people in transition from child to adult services

As Table 2 (Section 2) demonstrated, database searches identified very little research in the area of risk and adult social care with regard to people who misuse substances; black and ethnic minority populations, and young people in transition from child to adult services.

People who misuse substances

Within the small (Turning Point, 2006; Didlock and Cheshire, 2005; Warburton *et al.*, 2005) body of literature identified in this review, studies focused on service users' perspectives of risk and its management in everyday life. The importance of seeking to maintain normal life, its usual patterns/routines and also presentation of 'the self', especially, the idea that one was 'in-control' and coping was noted. The authors exploring risk and alcohol misuse amongst parents (Turning Point, 2005; Didlock and Cheshire, 2005) highlighted the important wider effects this could have on the family as a whole, particularly children. Indeed, parents, especially mothers were aware of the risks and dangers their alcohol misuse could bring, for example, children taking on additional caring and domestic responsibilities. A lack of co-operation between different service providers, especially children's and adult services was also noted and more co-ordinated working advocated. The views of practitioners were largely absent from these studies.

Transition from child to adult services

In the small number of studies (12) exploring the transition from child to adult services (largely transition experiences of young people with disabilities and/or serious chronic health conditions) where issues of risk were noted, albeit often briefly, risk was discussed largely in terms of independence issues. Research examined the risks (either health, physical or social) that young people may face pursuing greater independence in their everyday lives. As the majority of these studies drew on samples of disabled young people, the research was frequently grounded in the ideas and principles of normalisation theory. In addition, the studies reported focused on the attitudes and experiences of young people, including those with learning disabilities and their parents rather than practitioners.

The concept of 'adolescence' was also an underlying theme. Adolescence is frequently presented as a separate but troubled phase in the life-course, neither childhood nor adulthood. This ambiguity can lead to a questioning of young people's competence. Amongst the literature, risk taking and its management raised issues of, for example, the importance of peer group acceptance (Atkin and Ahmad, 2000; Morris, 2000; Schur *et al.*, 1999), control and acceptable levels of parental participation in risk decision making (Stanley *et al.*, 2004).

People from black and minority ethnic cultures

Database searches identified only a small number of studies (three, see Table 3) specifically focusing on issues of risk and black and minority ethnic participants and within these studies', quite specific and disparate groups of participants from black and ethnic minority groups were sampled. Some studies exploring other groups and issues such as older people and direct payments (Clark, 2006; Daker-White *et al.*, 2002) included sub-samples of people from black and ethnic minority communities, however, these were only a small part of the total study sample and ethnic/cultural issues were often not key or separate areas of consideration.

Research focused largely on the views of service users and informal carers rather than service providers. Informal carers, especially carers of older people, highlighted the importance of cultural sensitivity and understanding when assessing risk (Help the Aged, 2006; Daker-White *et al.*, 2002). However, the importance of ethnicity and cultural ideas within perceptions of risk was not always found to be of primary importance, similarities with white service users and their families were noted. In Atkin and Ahmad's (2000) study of young people with thalassaemia, although ethnic and cultural ideas were found, they were not a key factor in these young people's medical non-compliance. Western ideas of independence shared with white peers were frequently more important.

No research was found which examined the ethnicity of practitioners and its impact on risk assessments. Indeed, issues surrounding professional ethnicity and the ethnicity of service users and informal carers, and how this might impact on risk have received little research attention.

4. Gaps identified in the evidence base

This review has indicated that there are a number of gaps in the evidence base surrounding risk and adult social care where more research would be advantageous, these are highlighted below.

Voices of mental health service users and their informal carers

As noted above, the voices and everyday experiences of mental health service users and their informal carers were largely absent within the literature reviewed; the focus was generally on the risks and dangers mental health service users posed to others, as viewed by practitioners.

More research is needed on:

- Service users' experiences of risk and how they are managed in their everyday lives, especially the risk of self-harm, stigma, social isolation and increased surveillance in the community and negative effects of medication.
- Informal carers experiences of risk and its management both in their own lives and the lives of service users.

Socio-economic issues

Risk and gender

The role of gender in shaping the attitudes and behaviours of service users and carers has received little research attention in any area of adult social care. Apart from Atkin and Ahmad's (2000) study of young people and Horton and Arber's (2004) research with carers, the vast majority of studies reviewed either, did not explore gender differences or drew on gendered samples, i.e. samples of predominately female carers.

- More research is required on the role and impact of gender on service users and carers perceptions of risk and its management in different areas of social care.

Gender differences between staff were noted, especially with regard to adults with learning disabilities and sexual abuse (Browne *et al.*, 1994; Cambridge and Carnaby, 2000), however

- More research is needed examining gender differences between staff in other areas of social care, such as mental health, older people, and substance misuse.

Ethnicity, culture and risk

There is very little specific research exploring perceptions of risk and its management by different ethnic and cultural groups and amongst different types of participants (service users, informal carers and practitioners) from different ethnic backgrounds. In general, the research identified was based on very small samples and limited to specific areas, such as mental health.

- More research is needed with larger and more specific samples, exploring possible differences between different groups of black and ethnic minority service users, carers and practitioners and their white counterparts.

Material resources

The importance of limited material resources shaping practitioners perceptions of risk and how it is managed was discussed in the literature, especially the idea of risk as a criterion for resource allocation (for example, Heyman, 2005; Postle, 2002; Healey and Yarrow, 1998). In contrast, there is less research on risk and socio-economic circumstances, especially the material resources that carers and service users themselves have to draw upon. The limited research identified focused on two

groups; parents of adults with learning disabilities (Heyman and Huckle, 1993a, 1993b) and direct payment recipients (Flynn, 2005 Clark, 2006), however, this research, as the authors' themselves note, was tentative.

- Additional research is required on how socio-economic circumstances and access to resources amongst carers and service users in other areas of adult social care impacts on risk perceptions and management.

Disability

There appears little literature exploring risk and adult social care for people with a range of impairments, the focus has been predominately on learning disabilities.

- More research is required exploring the risks service users with physical disabilities, sensory impairments or multiple disabilities face in their everyday lives. Are these risks different to those encountered by adults with learning disabilities and their carers?

The review also found little research exploring how younger disabled people or those with fluctuating levels of impairment adapt to changed circumstances and physical functioning in relation to risk taking and its management. In addition, although research on risk and adults with learning disabilities was grounded in the theoretical framework of normalisation there was an absence of research exploring risk from a broader social model perspective, particularly, the risks created by a disability society. These are two important areas for consideration.

Risk and psychological well-being

The relationship between risk taking and psychological well-being was noted in research on older people, especially in the context of 'covert' risk taking (Clark *et al.*, 1996a, 1996b). However, the risk of damage to psychological well-being has received little consideration.

- Future research could explore how risks of damage to psychological well-being are experienced by different groups of service users and how these are managed by others.

Technology and IT

'Smart technology' (such as electronic alarm systems) and risk management is an emerging area but, as yet, has a very small evidence base (mainly pilot studies: Valletly *et al.*, 2006; Kelly, 2005). Despite this, interesting issues, such as independence for service users and 'peace of mind' for users and carers have been highlighted. More research is required on how 'smart' technology is viewed and

experienced as a means to reduce risk by the different parties (service users, carers and practitioners) and groups of social care users.

- Areas of potential interest include how 'smart' technology' impacts on practitioners' practice, feelings of security and/or surveillance for users and carers and, resource allocation.

Risk in the context of self-directed support arrangements

This review has identified some research evidence on the identification and management of risk by users of direct payments (Clark, 2006; Flynn, 2005; Ungerson, 1999). This research is much less extensive than evidence on the benefits of self-directed support arrangements and is mainly small scale and/or conducted in a limited number of localities. The expansion of direct payments to a wide range of different groups of adult service users and the introduction of other self-directed support mechanisms such as, In Control and individual budgets means that more extensive research is urgently needed. Moreover, individual budgets and In Control open up opportunities for close relatives and friends to become paid carers in more flexible and informal ways than currently occurs through the employment of personal assistants by direct payment users.

- More research is required on what risks arise for service users as a result of employing a personal assistant or for carers being paid by an individual budget holder and how can these be managed.

Research methods

The research identified in this review has largely involved qualitative methods and drawn on relatively small samples from specific geographic locations. There is a clearly a dearth of large scale, widely generalizable studies.

- More research is required with larger, more diverse samples from a range of geographical or social care settings.

Some studies (see Clarke *et al.*, 1998; Wilson, 1994) have noted how views of what is risky behaviour and how it should be managed can alter over time. Longitudinal research provides an opportunity to track these changes and explore how they impact on perceptions of risk and its management, however, only a small number of studies reviewed provided a longitudinal perspective, specifically collecting data at different stages of risk planning and management or from participants on more than occasion.

- More longitudinal research between different groups of service users and their carers would be advantageous.

5. Discussion

This paper presents an overview of current literature surrounding perceptions of risk and the different management strategies adopted by different groups of people in adult social care. The review had specific objectives and thus set clear study parameters in terms of the scope of the evidence base to be searched and the adult social care service users to be included. The researchers recognise that setting parameters leads to the exclusion of some empirical research which may be relevant but does not meet the project's search terms. Additional and/or more peripheral databases or websites could have been searched and grey literature included, however, in light of practical limitations (time and resource), a thorough search of the evidence base was conducted from a range of relevant sources.

The review has demonstrated that different people (service users, carers and practitioners) in different types of social care view and rationalise what is 'risky' behaviour, its costs and benefits in different ways and thus seek/apply different management strategies. However, beneath this diversity there are important cross-cutting themes; five key themes can be identified.

Risk and the search for a 'normal life'

'Risk' was explored in the context of pursuing a 'normal' (or what is perceived as 'normal') life. Although theoretically grounded in learning disabilities, 'normalisation' ideas and strategies have been extended to other areas of social care such as, older age, adults who misuse substances and young people in transition to adult services. Research examined how a number of 'everyday' risks were viewed, the 'normalisation' strategies actively developed and potential consequences for different groups of users and/or carers. 'Risk' was frequently associated with issues of empowerment and viewed positively rather than negatively as a potential learning experience. It could also be a means to strive for/redefine continuity in one's life or seek acceptance amongst peers/the wider community.

Risk and the importance of socially perceived competence

Research demonstrated that issues of perceived competence (or lack of competence) influenced both perceptions of risk and its management by different groups of people (service users, carers and practitioners). Although the issue of competence emerged as a theme for all groups of service users, it was particularly important for mental health service users and young people moving to adult services. In the former, issues of being 'dangerous' and 'out of control' emerged and in the latter, 'adolescence' was viewed as a potentially risky period in the life course. Research demonstrated that these stereotypes could effect the availability of opportunities (especially for service users) to participate in decision making s about risk and engaging in risk-related behaviour.

Risk and strategies to gain or maintain control

Evidence demonstrated that controlling risk can take different forms, including:

- controlling personal behaviour– what an individual can or cannot do
- controlling the information and/or knowledge given to or received by others
- controlling the physical and/or social environment experienced and accessed by others.

Active controlling strategies employed by service users, carers and practitioners involved negotiating or re-negotiating the boundaries of what was 'acceptable/unacceptable' or 'appropriate/inappropriate'. These strategies have important psychosocial effects on the lives and experiences of both service users and informal carers; this was most clearly demonstrated by the 'covert' risk management strategies developed by older people and their feelings of well-being, frequently underpinned by concepts of independence and choice.

Risk in different organisational contexts

Different organisational settings had an important impact on how 'risk' was viewed and subsequently managed by service users, carers and practitioners. Research explored the organisational context within which different practitioners worked, especially different procedures adopted and their ethos, and also providing care and support in domestic or informal settings (particularly, service users' homes). In the latter, potential tensions between risk taking as a private issue for service users and carers and risk management as a public issue for practitioners came to the fore.

Risk and the importance of knowledge and experience

The importance of personal knowledge and experience when assessing 'what is risky' behaviour and how it should be subsequently managed was paramount. Research highlighted that practitioners, carers and service users prioritised different types of knowledge and experience and this led to very different approaches to learning about risk and its management. For practitioners, this was particularly pronounced in terms of the length and type of their experience, especially, differences between official guidance and personal intuition. For carers, personal knowledge and experience of the person they supported and for service users, personal knowledge of one's illness/condition was paramount.

This scoping review focused on empirical research rather than theoretical or general discussions of risk and adult social care and has demonstrated that evidence is not evenly balanced in terms of either the type of social care services or participants involved. Research focused on three 'high' profile groups: older people, adults with learning disabilities and those with mental health problems. Practitioners' perspectives also predominated, studies reporting only the views of service users or carers were noticeably absent. One could argue that this reflects the state's role and pre-occupation with risk management rather than exploring and seeking to understand service user and carer ideas of risk and their preferred management

strategies. This, in turn reiterates Lupton's (1999) aforementioned distinction between 'technico-scientific' and 'socio-cultural' process and also reinforces Taylor-Gooby's (2006) idea that current welfare policies focus on 'rational' rather than 'non-rational/affective' ideas and thus present a partial understanding of risk and hence with limited public acceptance or meaning. Recognising these limitations is important, indeed, the gaps identified in this paper highlight the need for more research exploring user and carer perspectives and further research in some specific areas of social care.

Individual reflexivity and its associated themes of 'choice' and 'responsibility' (as noted in the introduction) raise ever-present tensions for 'risk' and social welfare in late modern society. Blame and fear of litigation for practitioners, whether real or perceived was also a very real issue. Three key areas of potential conflict have come to the fore (see also Alaszewski and Horlick-Jones, 2002; Shaw and Shaw, 2001) in this review:

- Right of service users to take risks or make the choice to undertake 'risky' behaviour and learn from experience versus responsibility of practitioners (or others) with a 'duty of care' to protect users from harm and/or potential danger.
- Right of service users to take risk versus responsibility of practitioners to protect others, including members of the wider community from harm and/or potential danger.
- Right of service users to take risks in their own home (or other informal settings) versus right of paid carers to have a safe working environment.

Tensions in the final area may become more pronounced and pertinent as different approaches to increasing choice and control that users can exercise over their social care are prioritised and developed (via direct payments, In Control and individual budgets). Indeed, the significance of balancing rights and responsibility has been recognised in the aforementioned policy guidance *'Risk, Responsibility and Regulation – whose risk is it anyway?' (2006)* and discussion paper *'Making Choices: Taking Risks'* (2006). In addition, the DoH's recently published *Risk and Choice Framework (2007)* seeks to establish clearer and more informed guidance for risk and its management in adult social care. These are potentially important developments, recognising that 'risk' needs to be addressed with standards set and advice provided. However, developing guidance, especially risk guidance (re the divergence between technical v socio-cultural) is extremely complex because, as research has demonstrated, how risk is viewed, rationalised and managed by different people (service users, carers and practitioners) in different areas of social care varies. Setting standards and striving for greater uniformity are central in order to work towards greater equity; however, flexibility is also important, as 'risk' is subjective, dynamic and contextually grounded. Marrying these potentially conflicting demands together will not be easy, especially if, as noted above and the balance of

research evidence identified by this review suggests, the state continues to prioritise the idea of (or presumption that one can/should) control risk.

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**Risk and Adult Social Care:
What Does UK Research Evidence Tell Us?**

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